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# Exemplar models and support for older carers and carers of people with dementia: informing commissioning

NHS England Commitment to Carers



The Open  
University

University of  
**Kent**

School of  
Social Policy,  
Sociology and  
Social Research



Melanie Henwood Associates

Health & Social Care Consultancy

Melanie Henwood, Mary Larkin and Alisoun Milne

October 2018

## Acknowledgements

This review was commissioned by Jennifer Kenward, Head of Patient Experience, and Carers Lead at NHS England; we are grateful to her for her support and interest throughout the review. The Principal Investigator for the project was Dr Mary Larkin, Senior Lecturer at The Open University; the co-lead was Dr Alisoun Milne, Professor of Social Gerontology and Social Work at the University of Kent. Dr Melanie Henwood, an independent research consultant, was the Research Associate for the project who designed and undertook the research, carried out the analysis, and wrote the report.

We would like to acknowledge the help and input of respondents who completed an on-line survey, and of the many people who gave freely of their time in agreeing to be interviewed and to share their insights with us.

Finally, we are particularly grateful to the participants at a consultation workshop in February 2018 who helped us refine our thinking and conclusions, and to graphic facilitator Pen Mendonça who captured the discussions with her distinctive visual images.

### Further Information

Further information can be obtained by contacting the research team through Dr Mary Larkin at the Open University.

[Mary.Larkin@open.ac.uk](mailto:Mary.Larkin@open.ac.uk)

Or by contacting research consultant Dr Melanie Henwood

[melanie@henwood-associates.co.uk](mailto:melanie@henwood-associates.co.uk)

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## Executive Summary

1. This is the report of a project commissioned by NHS England in support of its Commitment to Carers programme. The focus of the work was to scope exemplar models of support for older carers, and carers of people with dementia (of any age). The project reviewed existing literature and knowledge and used this as the foundation for examining developments with invited third sector organisations using an on-line questionnaire and additional semi-structured interviews. The work took place between May 2017 and March 2018 and included a consultation workshop in February 2018 with NHS England and other key stakeholders to refine messages and conclusions.
2. The report describes the work undertaken and presents an analysis of findings, together with conclusions and recommendations for NHS England. Section 1 explores the NHS England Commitment to Carers programme which was established in 2014. This forms part of its response to fulfilling the mandate from the Department of Health that the NHS should become ‘dramatically better’ at involving patients and their carers, and empowering them to make decisions about their own care and treatment. The Commitment to Carers is based around eight priorities which are: raising the profile of carers; education, training and information; service development; person-centred, well-co-ordinated care; primary care; commissioning support; partnership links, and the NHS as an employer. The present review is especially relevant to commissioning approaches, and to partnership, but as the report highlights, many of the other priorities also find resonance in the findings.
3. In Section 2 we outline and consider the wider context to this review both in the policy context of health and social care, but also in terms of research evidence and knowledge. Any discussion of support for carers needs to be considered against the framework of the 2014 Care Act which was intended to introduce parity of esteem between carers and the people they support, and to strengthen carers’ rights (such as to an assessment of need, while local authorities have a duty to meet carers’ eligible needs. Local authorities also have a duty to promote wellbeing and to support independence. The Act also carries a duty for local authorities to cooperate with other relevant bodies and to aim to integrate care and support with health provision.
4. These themes are further underlined by the NHS Five Year Forward View, published in 2014, and by the ‘Next Steps’ document in 2017, both of which set out a new strategic direction for the NHS, focusing on prevention and better integration of primary and secondary care, as well as of health and social care. New ways to support carers

are part of this approach and include recognition of the need to focus on groups of carers who may be the 'most vulnerable' (including older carers).

5. The Carers Strategies are also a relevant part of the policy landscape; the first national strategy was introduced in 1999, since when there have been various updates and iterations, and a Carers Action Plan is currently expected in advance of the publication of the 2018 Green Paper on funding social care.
6. Existing research and knowledge on carers have informed the approach and understanding of the project. In Section 2 we outline some of the main dimensions of this knowledge that are especially relevant to the review, and we start by examining the importance of relationships in caring for older people, and for people with dementia, particularly in terms of dyadic relationships. Older carers are likely to be caring for a spouse or partner, and the relationship is often characterised by co-dependency and mutual support, usually developed over many years. Older carers are also more likely to be caring while also managing their own health needs and increasing frailty.
7. Despite the intensity of much caring in later years, especially when supporting a partner with cognitive decline, older carers are less likely to identify themselves as carers, and more likely to view what they do in terms of their commitment and relationship with their partner or spouse. Older carers are also to be found with lifelong caring responsibilities for their now adult children with physical or learning disabilities. Such care can become more difficult as both carer and cared for become older, and worry about future care arrangements if a carer should pre-decease the person they support can be profound.
8. There is considerable overlap in the population of older carers, and carers of people with dementia, but not all people with dementia are elderly, and neither are all their carers. Caring for a person with dementia often brings specific pressures associated with changed personality and behaviour, and these demands are recognised to present risk factors for predicting carer stress and the likelihood of requiring permanent residential care. The stigma which surrounds dementia can add to the difficulties and increase the social isolation of carers and those they support who find it increasingly difficult to participate in daily social discourse.
9. Stigma associated with dementia can be a particular issue in some minority ethnic communities where there is a lack of awareness of the condition as a disease, or of services that may help in managing situations and symptoms. Carers in these

communities will face the same difficulties as any other carer of someone with dementia, but with the additional issues associated with cultural barriers and stereotypes, which can increase social exclusion and poor health outcomes for both the carer and the person with dementia.

10. Young onset dementia is relatively rare but receives much less attention or recognition than dementia among older people. This leads to delays in correct diagnosis and can mean that once diagnosed there are few services to meet their needs. Unlike older people with dementia, those with younger onset may often be physically fit and strong which can lead to challenges if they experience psychological disturbance. Younger onset dementia also brings additional pressures for carers and families because of the stage of life at which it has an impact. These are likely to be people who are still in paid employment, have financial responsibilities such as mortgages, and may still have dependent children or young adults to support.
11. Knowledge about models of support for carers indicates that evidence for 'what works' is relatively thin, inconsistent and based on evidence gathered at a local level. The limited evidence in support of respite, for example, is nonetheless accompanied by qualitative evidence from carers about the apparent perceived value of such support. Meta reviews of evidence on interventions to support carers have concluded that the best evidence for effectiveness is for education, training and information interventions that enhance carers' skills and knowledge.
12. Lack of evidence for effectiveness is not the same as evidence that there is no positive impact, and the inconclusive nature of evidence points to empirical issues such as the lack of a theoretical underpinning for interventions, or lack of clarity over appropriate measures of outcomes. However, the evidence which does exist suggests that positive impact is associated with contact outside carers' normal networks; similarly, positive impact on carers' mental health and wellbeing may be associated with psychosocial interventions, and with sharing and learning from others. 'Carer resilience' emerges from the literature as a term to describe the cumulative effect of a range of interventions and support that together may be beneficial.
13. In Section 3 we present the findings from exploring models of support with the third sector, drawing on the responses to an on-line questionnaire and to subsequent fieldwork and interviews. Both stages of work were informed by an understanding of the context outlined in Section 2. Invitations to complete the survey were sent to individuals in 19 organisations; two organisations indicated that they did not think the

content was relevant to them and declined to participate; of the 17 remaining, responses were received from 9 participants (Age UK; Carers Federation; Carers First; Carers Trust; Carers UK; Dementia UK; Parkinson's UK; Royal Mencap Society, and The Stroke Association). We undertook the survey on the basis of anonymity of individual responses and our analysis does not link the material to individual organisations.

14. Respondents were asked whether they have developed models of support for older carers under a number of types of provision, and to indicate where these also provided for carers of people with dementia. In addition, respondents were asked if they had developed models of support for carers of people with dementia who were not also older carers. The most frequently identified models of support related to peer support and befriending, and to educational/coping support and resilience development. High proportions of responding organisations indicated that they were also providing for carers in these groups in BAME and LGBT communities, but additional comments indicated that this was largely indicative of an inclusive approach of services rather than specific models that might address distinctive needs.
15. Specific models of support for carers of people with younger onset dementia were relatively absent, and again respondents indicated that such needs might be met within generic inclusive approaches.
16. Fieldwork and semi-structured interviews built on the findings from the survey and 6 of the 9 responding organisations chose to participate in further exploration of the issues. Additional contacts were identified from the team's networks, and interviews took place with 13 participants. The fieldwork generated a rich resource of qualitative material; all interviews were digitally recorded and fully transcribed, and content analysis took place with NVivo software with coding of key themes and issues.
17. In addition to identifying models of support, themes in the interviews included wide ranging insights into the situations and experiences of older carers and carers of people with dementia (including carers of people with younger onset dementia). Models of support identified included a considerable amount of generic activity (i.e. for all carers), while some was more specific and concerned with the carers of people with particular long-term conditions. Our analysis focuses on the main cross-cutting themes, and in particular these concerned: information and practical help (including sub-themes of: beyond diagnosis; signposting; locally based community support; respite; carer hubs, and dementia hubs); relationships (including sub-themes of: peer



support; co-dependency; and organisational relationships); model development (including contracts and tendering), and outcomes.

18. Our conclusions echo and reinforce many of the central messages identified in wider research and knowledge about supporting carers. Thus, for example, we found befriending and peer support, and approaches focusing on developing carer resilience were highly valued. We highlight that it is not always a specific intervention alone that makes a difference to carers, but it is the style of the service, and a combination of elements that provide valued support for carers and contribute to their resilience and capacity to sustain their identity. In particular, it is not simply the 'what' of a service, but also the 'how'; or what is distinctive about the approach of a service or a specific intervention that is valued by those who use it, and impactful.
19. It was relatively rare for models of support to be identified which had been developed with an underlying theory of change, without which identifying outcomes or understanding the appropriate dimensions of outcomes is problematic. This is particularly important in respect of commissioned services, and there are implications for how commissioners such as CCGs and local authority partners understand the interventions of the third sector and develop appropriate reporting and performance monitoring. Developing innovative approaches is also reliant on a conducive commissioning environment that provides some level of funding security over an extended timescale, rather than through short term contracts or annual tendering. This is particularly the case for small organisations that lack capacity to invest in staff and project development without such assurance.
20. This is a timely piece of work that fits with NHS England's continued Commitment to Carers programme and has the potential to help steer future directions in satisfying the mandate from the Department of Health on improving support for carers and enabling them to define what matters most in such support. There would be merit in exploring more fully some of the models we have identified and in supporting their adoption in other sites. We recommend that NHS England should give consideration to supporting such developments through further testing in pilot sites. The areas we have identified that offer the most promising directions for development are: building carer resilience; reducing carer isolation and loneliness; living a life beyond diagnosis; reimagining respite; and space and scope to expand.

## 1. Introduction

1.1 The Open University, Health and Social Care Department, was invited by NHS England to tender for a piece of work in support of its Commitment to Carers programme. The specification identified the requirement to:

- Scope exemplar models for older carers and carers of people with dementia.
- Engage with voluntary sector partners to scope and understand the work relating to older carers, including volunteer networks, how these networks provide support for people caring for someone with dementia, and how these networks strengthen the bonds that support people within their own communities.
- Provide recommendations for the development of commissioning support resources to connect commissioning processes to local population intelligence and positive practice models.

1.2 The contract was awarded to the Open University under the direction of Dr Mary Larkin, and Professor Alisoun Milne (University of Kent); the work was undertaken primarily by independent research consultant, Dr Melanie Henwood. The work was conducted in stages from May 2017 to March 2018. This report describes the work undertaken and presents an analysis of findings, together with conclusions and recommendations for NHS England. We begin by exploring NHS England's Commitment to Carers, and in Section 2 we set out the wider policy and research context to the project. Section 3 presents the findings from our work and analyses the implications, and we conclude in Section 4 with recommendations for future commissioning and testing of models to develop the best local support for carers.

### Background: The Commitment to Carers

1.3 NHS England's Commitment to Carers (NHS England, 2014b) acknowledged the importance of carers to the NHS, and recognised that carers need to be supported and nurtured:

*"Carers are a hugely important asset to the NHS. However, too often carers do not receive the recognition and support that they need and deserve from the NHS. We need to do more to help identify, support and recognise their vital roles. Helping carers to provide better care and to stay well themselves will contribute to better lives for those needing care and more effective use of NHS resources."* (NHS England, 2014, P.5)

- 1.4 The Department of Health's annual mandate to NHS England includes references to carers, particularly in the requirements for NHS England to help create the safest, highest quality health and care services (Department of Health, 2014, 2018). The 2014/15 mandate stated unequivocally that:

*"NHS England's objective is to ensure that the NHS becomes dramatically better at involving patients and their carers, and empowering them to manage and make decisions about their own care and treatment."* (Department of Health, 2014, paragraph 2.6)

- 1.5 Similarly, the latest mandate (2018) emphasises that as part of the overall objective of helping create the safest, highest quality health and care service, patients, their families and carers should be:

*"involved, through co-production, in defining what matters most in the quality of experience of services and assessing and improving the quality of NHS services."* (Department of Health, 2018, P.16)

- 1.6 In addressing the need to better involve carers, NHS England held a number of participation exercises which informed the Commitment to Carers and identified what is important to carers. The key themes to emerge from the consultation are summarised in Box 1.1 below

**Box 1.1 Themes from NHS England's Engagement with Carers 2013/14**

- Recognise me as a carer (this may not always be as 'carers' but simply as parents, children, partners, friends and members of our local communities);
- Information is shared with me and other professionals;
- Signpost information for me and help link professionals together;
- Care is flexible and is available when it suits me and the person I care for;
- Recognise that I also may need help both in my caring role and in maintaining my own health and well-being;
- Respect, involve and treat me as an expert in care; and
- Treat me with dignity and compassion.

Source: NHS England (2014), *NHS England's Commitment to Carers*, P.9

- 1.7 Based on the emerging themes NHS England developed 37 commitments structured around 8 priorities (see Box 1.2).

**Box 1.2: Eight Priorities of NHS England's Commitment to Carers**

1. Raising the profile of carers.
2. Education, training and information.
3. Service development.
4. Person-centred, well-coordinated care.
5. Primary care.
6. Commissioning support.
7. Partnership links.
8. NHS England as an employer.

Source: NHS England (2014), *NHS England's Commitment to Carers*, P.10

- 1.8 Under the priority of 'Commissioning Support', NHS England developed further work in 2014 with NHS Improving Quality, and with the Royal College of General Practitioners to gather case studies on good practice, and to use these as the foundation for identifying 10 'commissioning for carers' principles (Box 1.3). Each principle was accompanied by a checklist and an 'ask yourself' section intended for local use in identifying what already exists and what might need further development and investment.
- 1.9 The multiple layers of themes, commitments, priorities and principles indicate the complexity and multi-dimensional nature of support for carers that need to inform commissioning strategies and service development across both health and social care and related areas. NHS England's own review of progress focused on the eight priorities (and accompanying 37 commitments), and emphasised that there had been good progress but 'there is still more work to be done', and that this was 'the start of a journey, and a step in the right direction' (NHS England, 2015a). Nonetheless, the review indicated that of the 37 commitments, 32 have either been completed, or initial work has been done but further work would be required in 2015/16, and 5 commitments were ongoing into workstreams through 2015/16 (NHS England, 2015a).

**Box 1.3: Commissioning for Carers Principles**

1. Think carers; think family – make every contact count.
2. Support what works for carers, share and learn from others.
3. Right care, right time, right place for carers.
4. Measure what matters to carers.
5. Support for carers depends on partnership working.
6. Leadership for carers at all levels.
7. Train staff to identify and support carers.
8. Prioritise carers' health and wellbeing.
9. Invest in carers to sustain and save.
10. Support carers to access local resources.

Source: <https://www.england.nhs.uk/commissioning/comm-carers/principles/>

- 1.10 The present piece of work can be located particularly within priority 6 (commissioning support) and priority 7 (partnership links), as summarised in Box 1.2. That is to say, the project will assist in illuminating the impact of commissioning incentives, and system drivers in supporting carers, and will also reflect on the importance of partnership links between health, social care, and third sector organisations in shaping how carers can be supported as effectively as possible.
- 1.11 Before turning to present the findings and conclusions of the project, the next section turns to explore the wider context in greater detail, analysing both the evolving policy context, but also drawing on the evidence base that can be distilled from other research and knowledge.

## 2. The Policy & Research Context

### The Care Act

- 2.1 Developing appropriate support for carers is an objective that fits with a wider policy context, of which the mandate for NHS England is a core component. The Care Act 2014 (HM Government, 2014) was intended to:

*“make provision to reform the law relating to care and support for adults and the law relating to support for carers.” (P.1)*

- 2.2 The legislation introduced parity of esteem between carers and those they support; it strengthens carers’ rights to an assessment of need and places a new duty and power on local authorities to meet carers’ eligible needs. The general responsibilities under the Act create new duties on local authorities to ‘promote wellbeing’, and this applies equally to adults with care and support needs and their carers. A central aspect of promoting wellbeing is the focus on delaying and preventing care and support needs and supporting people to live independently for as long as possible. Integral to this vision is the need to intervene early rather than waiting until a crisis situation develops. Prevention is widely defined in the Act and accompanying guidance and includes interventions which may lessen the impact of caring on a carer’s health and wellbeing (including developing resilience and self-reliance). In addition, there is a requirement for local authorities to develop a local approach to prevention which is wider than care and support and embraces working in partnership to address the wider dimensions including public health, leisure, transport, housing services etc.
- 2.3 Other important aspects of the Act include a duty to co-operate, and of integration. Local authorities must co-operate with relevant authorities in respective functions relating to adults with needs for care and support, and relating to carers. Furthermore, under Part 1 of the Act there is a general responsibility for local authorities to carry out their care and support functions:

*“with a view to ensuring the integration of care and support provision with health provision and health-related provision” (HM Government, 2014, P.12)*

Where it considers that this would: promote wellbeing (of adults with needs for care and support and the wellbeing of carers); contribute to prevention; improve the quality of care and support for adults, and of support for carers.

- 2.4 The Act also includes general responsibilities on providing information and advice, and *a local authority “must establish and maintain a service for providing people in its area with information and advice relating to care and support for adults and support for carers”* (Clause 4).
- 2.5 The Care Act clearly provides the overarching framework within which we can locate models of support for older carers and carers of people with dementia. Full implementation of parts of the Act was initially postponed and subsequently cancelled, but this relates to the ‘capped cost’ model and self-funders’ care accounts and does not impact on the general responsibilities and duties outlined above.

### The NHS Five Year Forward View

- 2.6 The NHS Five Year Forward view (NHS England, 2014a), and the subsequent ‘next steps’ refresh (NHS England, 2017) together provide another essential part of the policy context. The Forward View set out the strategic direction on the future shape of the NHS. In addressing ‘a new relationship with patients and communities’, the document also emphasised the importance of prevention – with supporting carers identified as an aspect of this.

*“We will find new ways to support carers, building on the new rights created by the Care Act, and especially helping the most vulnerable amongst them – the approximately 225,000 young carers and the 110,000 carers who are themselves aged over 85. This will include working with voluntary organisations and GP practices to identify them and provide better support.”* (NHS England, 2014b, P.13)

- 2.7 The wider reforms envisaged by the Forward View focused on integrating primary and secondary care; physical and mental health care, and health and social care. The redesign of care was to be achieved by ‘new Vanguard models’ of care. The ‘Next Steps’ document reaffirmed the overall direction and indicated the priority of accelerating service redesign locally, particularly through Sustainability and Transformation Partnerships (STPs), and Accountable Care Systems (NHS England, 2017). Under the general objective of ‘prevention’, the next steps document also referenced carers in these terms:

*“Further action to identify and support carers. We will develop quality markers for Carer Friendly GP practices that promote carer identification, health checks, flu jabs*

and referral/signposting to advice and support in order to reduce carer breakdown and improve carer health-related quality of life. We will also help health and social care organisations to support carers, including young carers, to avoid reaching breaking point, so that they, and *cared-for person, will be less likely to end up in hospital.*" (NHS England, 2017, P.45)

## The Carers Strategy

- 2.8 The third element of the policy landscape is the carers strategy. First introduced in 1999, the National Carers Strategy has gone through a number of updates and iterations, as summarised in Box 2.1 below.

### Box 2.1 The evolution of the Carers Strategy

- **1999 Caring about Carers** The first National Strategy for carers, focused on improving quality of life for carers by improved information, support and care. Introduced a new Carers Grant for local authorities to enable carers to have breaks.
- **2006 New Deal for Carers** promised in the White Paper *Our health, our care, our say*.
- **2008 Carers at the Heart of the 21<sup>st</sup> Century** – this was the updated strategy and it presented a vision that by 2018 carers would be universally recognised and valued as fundamental to strong families and communities. Tailored support would enable carers to balance their caring responsibilities and a life outside caring. Five strategic outcomes were identified: carers will be respected as expert care partners, with access to services to support them; they will be able to have a life alongside caring; they will be supported so they do not suffer financial hardship; they will be supported to stay well and be treated with dignity; and children and young people will be protected from inappropriate caring responsibilities and have the support needed.
- **2010 Recognised, Valued, Supported (Next steps for the Carers Strategy)** identified four priority areas for the next four years: identification and recognition of carers; realising and releasing potential; a life outside caring; supporting carers to stay healthy.
- **2016: Carers Strategy call for evidence consultation** to better understand the needs of carers and what can be done to support them to “enjoy a happy and healthy life alongside caring.”
- **2018: Carers Action Plan 2018-2020** published, emphasising that carers are vital partners and their needs would be central to the forthcoming social care green paper.



- 2.9 The anticipated updated version of a national carers strategy failed to appear following the end of the consultation in June 2016, and the surprise General Election in spring 2017 created further delays. Furthermore, the election debates saw social care – and especially how adult care should be funded – become highly controversial and uncertain. A Green Paper is expected in 2018 (originally due in the Summer, but now scheduled for Autumn), and in his first speech on social care on World Social Work Day (20 March 2018), the then Secretary of State for Health and Care (Jeremy Hunt) stated that a principle for reform was that carers would be central to the new social care strategy. Ahead of the Green Paper, “we will publish an action plan to support them” (Hunt, 2018).
- 2.10 The cross-government Action Plan was published on 5<sup>th</sup> June 2018, and the Ministerial Foreword noted that the Plan was “*an essential step towards realising the Government’s commitment to value, recognise and support carers,*” (Department of Health and Social Care, 2018). The Action Plan identified five priorities emerging from the responses to the call for evidence:
- Services and systems that work for carers.
  - Employment and financial wellbeing.
  - Supporting young carers.
  - Recognising and supporting carers in the wider community and society.
  - Building research and evidence to improve outcomes for carers.
- 2.11 The Action Plan listed 64 actions being undertaken or planned across government departments over the next two years that address the priorities (including actions relating to older carers and carers of people with dementia). The Plan stated:
- “The action plan will deliver improvements for carers but it is not the whole story. We also want carers to be at the heart of the social care green paper. Carers are vital partners in the health and social care system and the needs of carers will be an important part of our new social care strategy.”* (Department of Health and Social Care, 2018, P.9)
- 2.12 This brief review of the recent and current policy context is relevant in contextualising our analysis of exemplar models of support. The other aspect of context to which we now turn concerns existing evidence and knowledge about models of support for older carers and carers of people with dementia.

## Messages from Research and Knowledge

- 2.13 The project for NHS England was informed by, and builds on, a scoping review of carer-related research and knowledge undertaken by the same research team (Henwood, Larkin, & Milne, 2017). We do not repeat the analysis here, but we draw on the review's findings.
- 2.14 The focus of the project for NHS England on older carers, and carers of people with dementia (of any age) is of importance for a number of reasons. It is often remarked that care takes place in the context of a relationship, and typically that is a dyadic relationship. Most care is provided by family members – typically caring for a parent/parent in law, spouse or partner, a child, sibling or other relative. The 2011 population census recorded 6.5 million people in the UK as carers (Carers UK, 2015a). People in mid-life (55-64) are the most likely to be carers, and this is the case for almost one in five of this cohort (18%) (Health and Social Care Information Centre, 2015). Some 40% of carers are aged 45-65, but a quarter of all carers are aged at least 65. Older carers are particularly likely to be caring for a spouse or partner, while middle aged carers are more likely to care for a parent or parent-in-law.

## Older Carers

- 2.15 Identifying carers can be problematic, particularly if people do not self-identify in these terms, and the literature demonstrates that people typically describe what they do within the normative expectations of their role as a partner, spouse etc (Corden & Hirst, 2011). Moreover, the choice or decision to become a carer – or to continue caring - may have little meaning in relationships characterised by long term obligation and reciprocity (Pickard, Shaw, & Glendinning, 2000). Within ageing couples there is often considerable co-dependency and mutual caring, as this comment highlights:

*“As couples age, both partners are more likely to need and give support, and the boundaries between providing and receiving care can be blurred.”* (Corden & Hirst, 2011, P.219)

- 2.16 Older carers differ from other carers in some important aspects, not least because as co-residents sharing a household they are typically more heavily involved in care-giving than are non-resident carers (Milne & Hatzidimitriadou, 2003).

*“Older carers can be distinguished from other groups of carers in a number of unique ways: they are more likely to live with the person they care for, care-giving is likely to take place within the context of a long-term relationship and there is a greater chance of carers having health problems of their own. Dementia is also more likely to be a feature of caring in later life.”*

*“There is clearly a high level of devotion to caring amongst many co-resident older carers; they often provide intensive care over a long period of time in very demanding circumstances with little or no support from services.”* (Milne & Hatzidimitriadou, 2003, P.12)

- 2.17 While older carers are likely to face complex and demanding needs from the person they support owing to multiple co-morbidity, they are often caring while also managing their own poor health and disability (McGarry & Arthur, 2001).
- 2.18 The demands on older carers also frequently reflect not only the physical infirmity of a partner, but also cognitive decline, including behavioural and personality changes that are associated with dementia, and following the incidence of stroke. The difficulties of coping with the onset of needs for care and support are particularly marked for carers of stroke survivors when there is a sudden transition to the carer role with no prior warning, and carers in these situations often experience strain and stress (Draper & Brocklehurst, 2007). The pressures on carers in such circumstances are also intensified by the experience of social isolation which can result because of difficulties associated with both the physical and psychological effects of stroke (Cheater, 2008; Quinn, Murray, & Malone, 2014). The quality of the relationship, and the perception of mutuality within the spousal dyad, are significant predictors of people’s capacity to continue caring, and without these factors present a breakdown in the caring relationship and permanent admission to care are more likely outcomes (Shim, Landerman, & Davis, 2011).
- 2.19 Research which assesses dimensions of carer ‘burden’ (i.e. both the physical and psychological impact of caregiving) has found older carers particularly likely to experience high levels of burden (Rinaldi, Spazzafumo, Mastriforti, Mattioli et al., 2005).

*“This is so probably because the spouse often suffers from age-associated chronic illnesses and providing care is more difficult than for an adult child when care needs*

*increase (...) Dementia can undermine the marital relationship, so that reciprocity can be lost.” (P.173)*

- 2.20 However, some evidence is contradictory; a narrative review of 18 studies for example found that while some results suggest that older carers find caring more challenging than younger carers, others suggest that older carers are better equipped to cope (Greenwood & Smith, 2016). Part of the difficulty in interpreting findings is the relative lack of research comparing older and younger carers, or carers and non-carers.

*“As a result, it is impossible to confidently say, for example, whether older carers find caring more or less challenging than younger carers or whether their quality of life is usually poorer than that of non-carers. Importantly, despite being more likely to have their own health conditions, some research identified here suggests older carers may have more positive perspectives and coping strategies and may identify rewards in caring more often than younger carers.” (Greenwood & Smith, 2016, P.168)*

- 2.21 Other evidence and information about older carers and their experiences is to be found in ‘grey literature’, particularly in reports and campaigns from the third sector. Carers Trust, for example, has undertaken work with focus groups and some individual interviews of older carers, the findings of which underlined the distinctive nature of older carers’ needs and experiences, and confirmed the challenges of caring while ageing (Carers Trust, 2016):

*“Over half the carers attending the focus groups and five of the seven individuals, had at least one health condition, these included high blood pressure, arthritis and heart problems. They experienced loss of strength and mobility, found they tired much more quickly and didn’t sleep well. Carers said it was really important to be organised as a carer but adjusting to change when you are older is much harder.” (Carers Trust, 2016, P.5)*

- 2.22 The findings by Carers Trust also illuminated some of the tensions that can develop in caring for a spouse, partner or relative, especially if their relationship was not good:

*“A small number of older carers said they were caring for a spouse, partner or parent who they had a challenging and difficult relationship with. This group of carers spoke about how they felt it was a duty to care as there was no one else to fulfil this responsibility of they did not.”*

And

*“A few carers who had come to the decision that they were no longer able to willing to care felt they had not been well supported to make this decision and were harshly judged by relatives and some professionals.” (Carers Trust, 2016, P.8)*

- 2.23 As Pickard et al point out (Pickard et al., 2000), older spouse carers are not a homogenous group, but rather they include a variety of types of relationship – from close and intimate relationships of many years standing, to relatively recent marriages or partnerships, to less satisfactory relationships, and:

*“In that these relationships form the foundation on which the caring relationship is constructed, they are very significant in framing the kinds of caring exchanges that take place. Moreover (...) despite the rhetoric of individual choice (...) the pull of obligation and reciprocity embedded in these relationships meant that, in practice, the concept of choice is largely irrelevant to some older carers.” (Pickard et al, 2000, P.732)*

- 2.24 Despite the evidence and knowledge about the reality of older carers’ experiences, and the increasing significance of the situation given the continued ageing of the population, it remains the case that older carers are relatively invisible in policy, practice and research on carers (particularly relative to the recent focus that has been directed towards ‘young carers’). Pickard et al point to the importance of older carers being given ‘real choice’ about the extent of their involvement in caregiving, and more effective support in the areas in which they choose to provide care:

*“Services must be designed with the needs and preferences of older carers in mind. An understanding of the context in which older carers operate, as well as of the consequences of inadequate support, may mean that professionals can anticipate their needs and be pro-active in offering help, rather than responding only to cries of despair.” (Pickard et al, 2000, P.742)*

- 2.25 The issue of choice is particularly important as Schulz et al highlight, given that lack of choice emerges as an independent risk factor for the negative effects of caregiving, and should be viewed as a marker for caregiver distress (Schulz, Beach, Cook, Martire et al., 2012).
- 2.26 Not all older cares are caring for a spouse or partner, nor indeed for a person with dementia, and ageing carers are also to be found with life-long caring responsibilities for their disabled children (particularly those with learning disabilities). This group of carers may be especially vulnerable after decades of caring, and with no plans in place

for what happens when they are no longer able to care or if they pre-decease the person they care for (Bowey & McGlaughlin, 2005; Bowey & McLaughlin, 2007). Perkins and Haley describe this "unique population of carers" characterised by the duration of their caring, alongside concerns about their own health status and ageing, and worried about the future (Perkins & Haley, 2013). They pointed to the changing nature of the relationship between parent and child, with the emergence of some co-dependency and mutual support:

*"The roles of carer and care recipient may evolve over time and become rather blended as both carer and care recipient age."* (Perkins & Haley, 2013, P.342)

2.27 Moreover, this finding of reciprocity appeared to exist regardless of the severity of learning disability, and because reciprocity impacts on carers' sense of satisfaction and reduces perceptions of burden, it can be a "potentially promising predictor of carer well-being." Reciprocity and co-dependency doesn't necessarily mean that the cared-for becomes the carer (although this can happen), but older parent carers also report reciprocal satisfactions in their relationship with their adult child (Cairns, Tolson, Brown, & Darbyshire, 2013).

2.28 However, older carers who have spent years caring for a disabled child can also reach the point of questioning their capacity to continue caring through later life, and considering whether it is 'time to let go'. Cairns et al undertook a small qualitative study with older parent carers of children with learning disabilities:

*"Participants described a life which consisted of long hours, demanding caregiving tasks, and receiving limited support and information from the outset. Despite the intensity of caregiving, all described their commitment to caring for their dependent offspring with learning disabilities. These findings highlight that older parent carers are an especially needy group."* (Cairns et al, 2013, P.80)

2.29 Some reported that they continued in their role as carer despite their own deteriorating health status because there appeared to be no alternative. In some situations this reflected older carers' lack of trust in service provision because of earlier negative experiences, but others were simply not aware of any support or care that might be available.

2.30 We have focused above on older carers who are often very elderly themselves, but the cohort of 'older carers' is a wide one and includes – at the other end of the spectrum – people in their sixties who might be supporting an ageing parent (often at a distance),

while also trying to juggle employment and other caring responsibilities for children who continue to live at home as young adults, and for grandchildren. This is the sandwich generation of carers (Carers UK, 2015b; Do, Cohen, & Brown, 2014; Grundy & Henretta, 2006)

### Carers of People with Dementia

- 2.31 Most – but not all – people affected by dementia are elderly, and the same is true of their carers. Dementia is a complex and progressive condition which causes a loss of cognitive, functional and mental capabilities (Bremer, Cabrera, Leino-Kilpi, Lethin et al., 2015). As Newbronner et al point out, there is no such thing as a ‘typical’ caring journey (Newbronner, Chamberlain, Borthwick, Baxter, & Glendinning, 2013). The way in which people are affected by dementia, and the capacity of carers to cope physically and emotionally will vary, but there are a number of ‘critical points’ in the caring journey from diagnosis through to end of life care, when there are vital opportunities for professionals and services to provide appropriate support and signposting, and when carers’ needs are particularly acute. They conclude that failure to recognise carers’ needs at these points *“risks the breakdown of care-giving and health and other costs for carers and the wider society”* (P.70).
- 2.32 Because of the intensity and range of care needs over time, dementia is often linked in research with ‘carer burden’. In general terms, higher intensity of caregiving is associated with negative health outcomes for carers. However, the strongest predictor of poor psychological health of carers is behavioural problems; Bremer et al examined the consequences of dementia care on carers’ health in 8 European countries and concluded:
- “After controlling for living conditions and disease severity, the impact of caregiving intensity reduced and the existence of behavioural problems emerged as a strong predictor for adverse health effects in almost all countries.”* (Bremer et al, 2015, P.1468)
- 2.33 Care recipients’ physical and cognitive impairment played ‘a minor role’ in predicting reduced carer wellbeing, compared with agitated or aggressive behaviour. Campbell et al, by contrast, report that it is not the level of cognitive function, levels of help required, or behavioural and psychological symptoms that are significant contributors

to carer burden, but rather it is the carer's sense of 'role captivity' (Campbell, Wright, Ovebode, Job et al., 2008).

*"The study has shown that it is not so much the 'objective' load on the caregiver that leads to burden but more importantly it is in how the caregiver perceives this load in terms of their previous relationship with the patient, their own confidence and efficacy in the role and the time they have to develop and sustain their sense of self."* (P.1083)

- 2.34 Similar conclusions have been offered through research with women in Spain caring for relatives with dementia which suggest that temporarily removing oneself from the caring role and connecting with other selves alleviates carer burden (Cuesta-Benjumea, 2011);

*"A close examination of the data shows that when caregivers act upon other identities such as being a grandmother, a wife, a mother, or a friend, they attain rest. Thus, it is of little relevance what the caregiver actually does or where she is, but it is fundamental who she is in her relations to others and the social space that she occupies."* (P.1794)

- 2.35 Much of the literature on the 'burden' of caring – particularly in caring for someone with dementia – has tended to focus only on the carer, rather than on both members of the dyad, and the relationship between them. However, research that takes account of the relationship between the carer and the person with dementia has found that aspects of the prior relationship impacts on the caring relationship and the way that roles of carer and care receiver are experienced. At the same time, living with dementia also impacts on the nature of the relationship within the dyad (Ablitt, Jones, & Muers, 2009). Carers who had a good prior relationship with the person for whom they now care, tend to experience less burden and distress; while those with less positive prior relationships *"are likely to experience higher levels of distress and burden, and may feel some resentment about their caring role"* (P.508).

- 2.36 In addition to the demands of caring is the impact of supporting someone with a condition such as dementia which still carries considerable stigma or social discomfort. This can be significant in increasing the social isolation of carers and those they care for. Charlesworth et al found carers of people with dementia had fewer opportunities to socialise, reported less social interaction and fewer friendships than non-carers (Charlesworth, Tzimoula, Higgs, & Poland, 2007).

- 2.37 Much British research on the experience of people with conditions such as dementia has focused on people from white British backgrounds and has taken little account of



how family members of different minority ethnic groups manage the situation or access services. Research which has been done has highlighted challenges around poor cultural and language awareness in services, and in part this is a reflection of wider inequalities issues in health and care services (Forbat & Nar, 2003). Stigma around dementia can be a particular issue for carers from some cultural groups and minority ethnic communities. Research into the experience of carers of people with dementia in Asian communities, for example (St. John, 2004), has highlighted a view that:

*“The illness is not conceptualised as an organic disease associated with old age, but as a result of it. This affects how families understand the needs of those with dementia and their carers.” (P.23)*

- 2.38 It is probable that there is a higher incidence of dementia among South Asian communities because they are more likely to experience known risk factors including hypertension, heart disease and diabetes, but referral and diagnostic rates are lower in this community (as in other BAME communities), and people with dementia present to services at a later stage in their illness. The lack of awareness or understanding of dementia is likely to contribute to low diagnosis, and also to pressures on carers, as Mohammed comments (Mohammed, 2017):

*“Older people and their family members may be unfamiliar with the symptoms of dementia and dismiss them as old age. These reasons may be amplified if the older person is unable to communicate potential symptoms to family members and/or the GP either due to lack of appropriate language or fluency of English (...) Older people and their families may believe that nothing can be done to help them, there could be a lack of awareness of available services, or how to access them.” (P.15)*

- 2.39 Essentially, he argues, for people to recognise dementia within the community, there needs to be recognition of dementia as a health care problem “a view not always present in older South Asians” (Mohammed, 2017, P.15). Work by Carers UK on BAME carers (Carers UK, 2011) similarly points out that these carers face the same challenges as all carers, but:

*“also face additional barriers, for instance cultural barriers, stereotypes and language, which can increase the chances of poorer health, poverty and social exclusion.” (Carers UK, 2011, P.5)*

## Young Onset Dementia

2.40 Not all carers of people with dementia are elderly, and dementia can also affect younger people (i.e. below age 65) although it is clearly more prevalent in old age. In looking at ‘carers of people with dementia’ we were concerned to identify the issues for carers – of any age – supporting people (also of any age) with dementia, and to consider their distinctive needs for support. Given the higher prevalence of dementia among older people, the situation of people caring for those with young onset dementia has received relatively little attention to-date, although this seems to be changing. Younger people with dementia account for around 5% of all people with dementia, and although many of their needs are similar, they also differ from older people with dementia. In particular, they are less likely to have the co-morbidities of long term conditions and disabilities that many older people with dementia have, and may well be physically fit. People with Down’s syndrome and other learning disabilities are at greater risk of developing early onset dementia, and this has become more apparent with the long-term survival of cohorts of people with learning disabilities.

2.41 The Alzheimer’s Society highlights the particular issues facing people with younger onset dementia (Alzheimer’s Society, 2008). People can experience symptoms that are different from those of older people who develop dementia, including problems with behaviour, vision and language. Accepting the diagnosis earlier in life can be particularly challenging, and the impact on the wider family is likely to be significant.

*“In general, younger people with dementia are more likely to:*

- Be in work at the time of diagnosis
- Have a partner who still works.
- Have dependent children.
- Have older parents to care for.
- Have heavy financial commitments, such as a mortgage.
- Be more physically fit and active.
- *Have a rarer and genetic form of dementia.”* (Alzheimer’s Society, 2008, P.11)

2.42 Carers of people with young onset dementia will be similarly likely to be younger and to have additional commitments and responsibilities. Because there may also be dependent children in the family, some of these young people are also likely to take on a caring role (Svanberg, Stott, & Spector, 2010).

- 2.43 Lockeridge and Simpson found evidence that carers of younger people with dementia experience greater emotional distress than carers of older people with dementia, and experience greater difficulty coping with challenging behaviour (Lockeridge & Simpson, 2013). Although the experiences of younger carers of people with early onset dementia are similar in many ways to those of carers of older people with dementia, there are also significant differences. Lack of public and professional awareness of early onset dementia increased carers' sense of stigma, and they sought to protect the person's identity as long as possible which could involve keeping the truth from a partner with early onset dementia.

*"Younger carers adopted a range of emotion and problem-focused coping strategies, though useful in the short-term, ultimately led to negative emotional and psychological outcomes both for carers and their partners with dementia."* (Lockeridge & Simpson, 2013, P.649)

- 2.44 The concept of selfhood for people with dementia recognises that although people can lose their skills and social roles, the "core concept of who the person is, their held concept of self, remains", but this has been little explored for people with younger onset dementia (Harris & Keady, 2009). This group of people diagnosed with younger onset dementia face unique and complex challenges:

*"These issues include difficulties of getting a timely and proper diagnosis, issues of selfhood and self-esteem, changing relationships within entire family structures, awareness of changes in self, workforce and retirement/financial issues, intense feelings of social isolation and being marginalized, off-time dependency and boredom, and lack of meaningful occupation."* (Harris & Keady, 2009, P.437)

- 2.45 Harris & Keady's research with younger people affected by early dementia, and their carers, focused on exploring the psychosocial impact of younger onset dementia on the selfhoods of the person and their carer. All participants were found to have experienced "a transition in their selfhood and identity from the time of diagnosis" (P.441). This is likely to be the case with people of any age affected by dementia, but:

*"Integral parts of selfhood, components that comprise anyone's daily sense of self, are affected by this diagnosis from one's identify as a worker, family member, sexual and social being and as an individual engaged in living. And for the younger individuals with dementia and their family members, the disease occurs 'off time', not in their older years, as most often expected, but in the prime of their lives."* (P.442)

- 2.46 Feelings of ‘loss, fear and abandonment’ typically followed diagnosis, with younger people and their families increasingly isolated. Furthermore, there is increasing recognition that carers of people with early onset dementia are subject to greater emotional stress, financial worries, and concerns about loss of employment or reduced hours (Rosness, Mjorud, & Engedal, 2011). Research into depression and Quality of Life (QoL) among carers aged 49 to 70 of people with early onset dementia found the youngest carers had the poorest Quality of Life *“suggesting that couples living together in a midlife situation experience most problems”* (Rosness et al, 2011, P.304).

### Models of Support

- 2.47 In addition to scoping knowledge about older carers, and carers of people with dementia, this project is especially concerned to identify models of support and interventions that appear worthwhile. Before we turn in Section 3 to explore the findings from the fieldwork, we briefly examine the wider knowledge about ‘what works’, and again we draw particularly on our recent scoping review which has synthesised the evidence (Henwood et al., 2017). As we noted, this is a complex area, and evidence is far from conclusive. Services developed specifically to support carers include respite and breaks from caring; while services provided to support the person needing care, may also indirectly benefit the carer.
- 2.48 Arksey et al reviewed the research on respite and short breaks for carers of people with dementia, and found evidence mixed and at times contradictory (Arksey, Jackson, Croucher, Weatherly et al., 2004):
- “Overall, however, the review found that on the basis of the outcome measures used and on the service that was offered, evidence of the effectiveness and cost-effectiveness of respite care and short-term breaks is limited.”* (P.8)
- 2.49 Despite this, they also found considerable qualitative evidence from carers about the perceived value of respite, and as the authors observed:
- “It would be wrong to assume that lack of evidence of effectiveness should be interpreted as evidence that respite is ineffective.”* (P.8)
- 2.50 Other reviews have reached similar conclusions; Mason et al, for example, conducted a systematic review of models of community-based respite for frail older people and their carers (Mason, Weatherly, Spilsbury, Arksey et al., 2007), and concluded:

*“Evidence from this review suggests that respite for caregivers of frail elderly people generally has a small effect upon caregiver burden and caregiver mental and physical health. There is tentative evidence that some caregivers benefit more than others, but caregiver satisfaction levels for all types of respite are generally high, and caregivers appear to be more satisfied with respite than with usual care.” (P.297)*

- 2.51 Other reviews have also found inconsistent or minimal evidence of the value of carer support interventions (Lopez-Hartmann, Wens, & Verhoeven, 2012), although almost all studies identify ‘some positive outcomes’ (Arksey, O'Malley, Baldwin, & Harris, 2002).

- 2.52 Two meta-reviews have also looked at international evidence on interventions to support carers (Parker, Arksey, & Harden, 2010; Thomas, Dalton, Harden, Eastwood, & Parker, 2016), and found the best evidence for effectiveness in respect of interventions to enhance carers’ knowledge and skills (education, training and information), but:

*“Beyond this, there is little secure evidence about any of the interventions included in the reviews. We must emphasise that this is **not** the same as saying that these interventions have no positive impact. Rather, what we see here is poor quality research, often based on small numbers, testing interventions that have no theoretical ‘backbone’, with outcome measures that may have little relevance to the recipients of their interventions.” (Parker et al, 2010, P.67)*

- 2.53 The updated meta review in 2016 (Thomas et al, 2016) found that most models of support had not been evaluated and only respite services were subject to systematic review. Nonetheless, some wider conclusions on what makes a difference to carers were offered:

*“However, what seems clear is that contact with others outside the carers’ normal networks (whether professional or other carers) may be beneficial, regardless of how delivered (...) there is potential for effective support in specific groups of carers. This includes shared learning, cognitive reframing, meditation, and computer-delivered psychosocial interventions for carers of people with dementia; psychosocial interventions, art therapy, and counselling for carers of people with cancer. Counselling may also help carers of people with stroke. The effectiveness of respite care remains a paradox, given the apparent conflict between the empirical evidence and views of carers.” (Thomas, et a, 2016, P.xx)*

- 2.54 Thomas et al also identified a range of interventions that “may have an effect” for carers of people with dementia; of people with cancer, and of stroke survivors; in the case of the former this included:

*“Opportunities to share with and learn from others (whether carers or professionals) may have a positive impact on depression and anxiety, and on subjective burden. Opportunities to reframe the way they think about dementia may have a positive impact on mental health and subjective burden and stress. Learning meditation techniques may have a positive impact on depression. Psychosocial interventions delivered via a computer may have a positive impact on depression and anxiety and on subjective burden and stress.”* (Thomas et al, 2016, P.97)

- 2.55 Thomas et al point out that the lack of evidence on outcomes is indicative of the dearth of good primary research on effectiveness of interventions, but it also points to the absence of underpinning theories of change surrounding many interventions; this is an issue we will return to later in the report.

- 2.56 Understanding ‘what works’ to support carers, and how interventions work, matters Parkinson et al (Parkinson, Carr, Rushmer, & Abley, 2016) suggest for the following reasons:

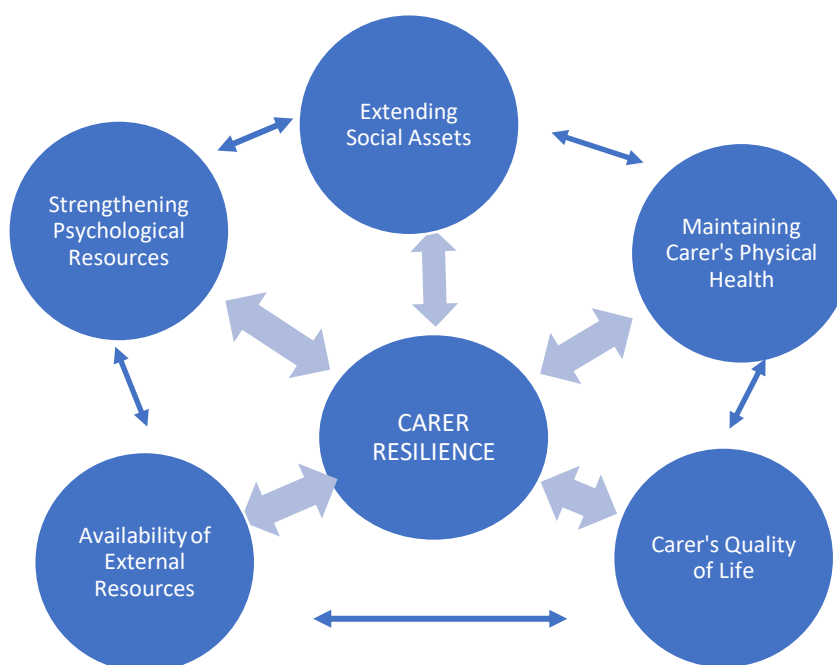
*“This would pave the way for the more strategic provision of family support that maximises those resources carers already possess while finding more effective ways to allocate external support, e.g. from formal health-care services.”* (P.291)

- 2.57 Their ‘rapid realist review’ of what works to support carers of people with dementia confirmed that what is absent from the research evidence is consensus about what works to support family carers, and, *“more fundamentally, ‘how’ the disparate array of strategies ‘work’”* (P.298). In trying to establish what it is that connects most carer support measures, Parkinson et al proposed a unifying principle of ‘carer resilience’, and argued:

*“Crucially, this offers a means to establish a more comprehensive, coherent and cohesive framework for supporting family carers that harnesses the benefits of multiple strategies. These can be usefully adapted, combined and strategically exploited around the clearer premise of ‘strengthening carer resilience’.”* (Parkinson et al, 2016, P.294)

- 2.58 The analysis offered by Parkinson et al identified five key areas that appear to contribute to carer resilience and resilience building. These are summarised the figure below.
- 2.59 Within each of the cells radiating around the central concept of resilience there are sub-components or themes which reflect both subjective and objective elements, and internal and external dimensions. The concept of resilience is based on an understanding that this is a process which can develop throughout life, in which case – the authors suggest - older carers “may actually be better placed than their younger counterparts in terms of their potential to harness and exploit this valuable resource” (P. 298). The model, and the programme theories which underpin it, are seen by Parkinson et al as iterative and subject to further refinement and testing. However, they provide a useful framework for introducing some overarching coherence across the multiplicity of types of support and intervention for carers and exploring if and how they contribute to enhancing and sustaining carers’ resilience.

**Figure 2.1: Generating Carer Resilience**



Source: Derived from Parkinson, M., Carr, S M., Rushmer R., and Abley, C (2016), 'Investigating what works to support family carers of people with dementia: a rapid realist review', Journal of Public Health, Vol 39, No. 4, pp 290-301.

## Summary

- 2.60 In this section we have set out the various dimensions of background and context to the project. The policy context framed by the Care Act and the NHS transformation agenda underlines the importance of locating carers within wider objectives of supporting prevention and promoting wellbeing, while pursuing greater integration of care and health services and developing new models of care. The 2018 Action Plan for carers provided a further opportunity to draw these elements together, and underlined the contribution of NHS England in its commitment to carers.
- 2.61 In briefly reviewing the knowledge and research relevant to this project we have focused particularly on older carers, and carers of people with dementia (including people with young onset dementia) and highlighted the challenges and demands of these different caring situations. Finally, we have considered the emerging evidence on what works to support carers, recognising that conclusions are tentative and that research does not point a definitive way forward on models of support. Nonetheless, there are some useful findings about the likely value of certain interventions particularly in terms of the subjective value to carers. For example, having contact with people outside carers' usual networks appears beneficial.
- 2.62 It is against this background and understanding that we developed the fieldwork for the project to further explore exemplar models of support, and we turn in the next section to describe and analyse our approach and findings.



### 3. Exploring Models of Support with the Third Sector

#### a) On-line Survey

- 3.1 Informed by our review and understanding of both the needs and characteristics of carers (of older people, and of people with dementia), and by the evidence about what models of support or types of intervention might work, we wished to explore approaches to support for these groups of carers being developed and applied by third sector organisations and their partners. An on-line survey was designed, tested and refined in Summer 2017. The survey explored inter alia: the use of volunteer networks; coping/educational interventions; respite services; technological support and interventions; memory services; dementia cafés (and similar models); befriending and peer support etc. We were interested to capture innovation, and to examine evidence of evaluation where possible. The survey was also an opportunity for us to invite expressions of interest from participants who wished to be involved in a second stage of the project enabling us to explore findings in greater depth.
- 3.2 We identified a 'long list' of key carer organisations, but also other bodies that we believed would also be involved in supporting carers because of the nature of their work (including, for example, Age UK; Dementia UK; the Stroke Association; MS Society; Parkinson's Society, among others). In total 19 organisations were invited to participate, and personalised emails were sent to named individuals within each organisation providing log in details and access codes to the on-line survey.
- 3.3 Initially it was planned to keep the survey open for one month, but two deadline extensions were made to accommodate holiday absences and give maximum opportunity for completion, and the survey was open for more than 6 weeks (from 18<sup>th</sup> July to 1<sup>st</sup> September 2017). Several rounds of reminder emails were sent to non-responders, and other email exchanges and telephone conversations also took place.
- 3.4 Responses were received from 9 out of the 19 organisations, a completion rate of 47%. However, two of the organisations invited to participate communicated with the team and indicated that they did not think the survey was relevant to their current work, although it was of interest to them. If the potential total of responding organisations is reduced to 17, this raises the response rate to 53%, which is considerably higher than is typically achieved in similar surveys.

3.5 The nine responding organisations were the following:

- Age UK
- Carers Federation
- Carers First
- Carers Trust
- Carers UK
- Dementia UK
- Parkinson's UK
- Royal Mencap Society
- The Stroke Association

3.6 We are very grateful to these participating organisations for their assistance with our work. We offered respondents anonymity in the way that we use their responses, and we do not identify individuals or their organisations in the analysis which follows. However, some of the exemplar models of support are particularly distinctive and may be more easily identified. Where this was the case we have obtained permission to identify the service. We turn now to consider the questionnaire responses and to outline the picture they describe of approaches to carer support.

#### Working with volunteers

3.7 Respondents were asked about if and how they engage with volunteers as part of their support for carers, and open text comments revealed a variety of ways in which volunteers are involved. Of particular significance, and mentioned by several respondents, was the role of volunteers in befriending carers (both individually, face to face, and through telephone services), and in providing peer to peer support. Volunteers are often either current or previous carers themselves and have personal experience and insights to share.

#### Models of Support

3.8 Respondents were asked to indicate whether they had developed models of support for older carers under a number of types of provision, and also to indicate whether these models provided for carers of people with dementia as part of this service. In addition, respondents were asked separately whether they had developed models of

support for carers of people with dementia who were not also older carers (and who would have been included in the first set of their responses. Figures 3.1 - 3.3 summarise the response frequencies (not all questions were answered by all respondents).

3.9 As figures 3.1 and 3.2 demonstrate, most respondents indicated that their models of support for carers of older people are focused primarily on:

- Befriending and peer support.
- Educational/coping support and developing carer resilience.

The role of such support is notable given the conclusions highlighted in the previous section regarding the importance of carers interacting with other people, and the benefits of information and coping training in developing resilience.

3.10 Responses also appeared to indicate most responding organisations are involved in support for older carers in rural areas, and for carers from LGBT and BAME communities. However, the additional comments offered by respondents generally indicate that this is indicative of an inclusive approach, rather than reflecting specific projects or models for these groups. The same point can be made in respect of support for carers of people with dementia, where the pattern of responses was very similar, and again is primarily a reflection of a generally inclusive approach, for example:

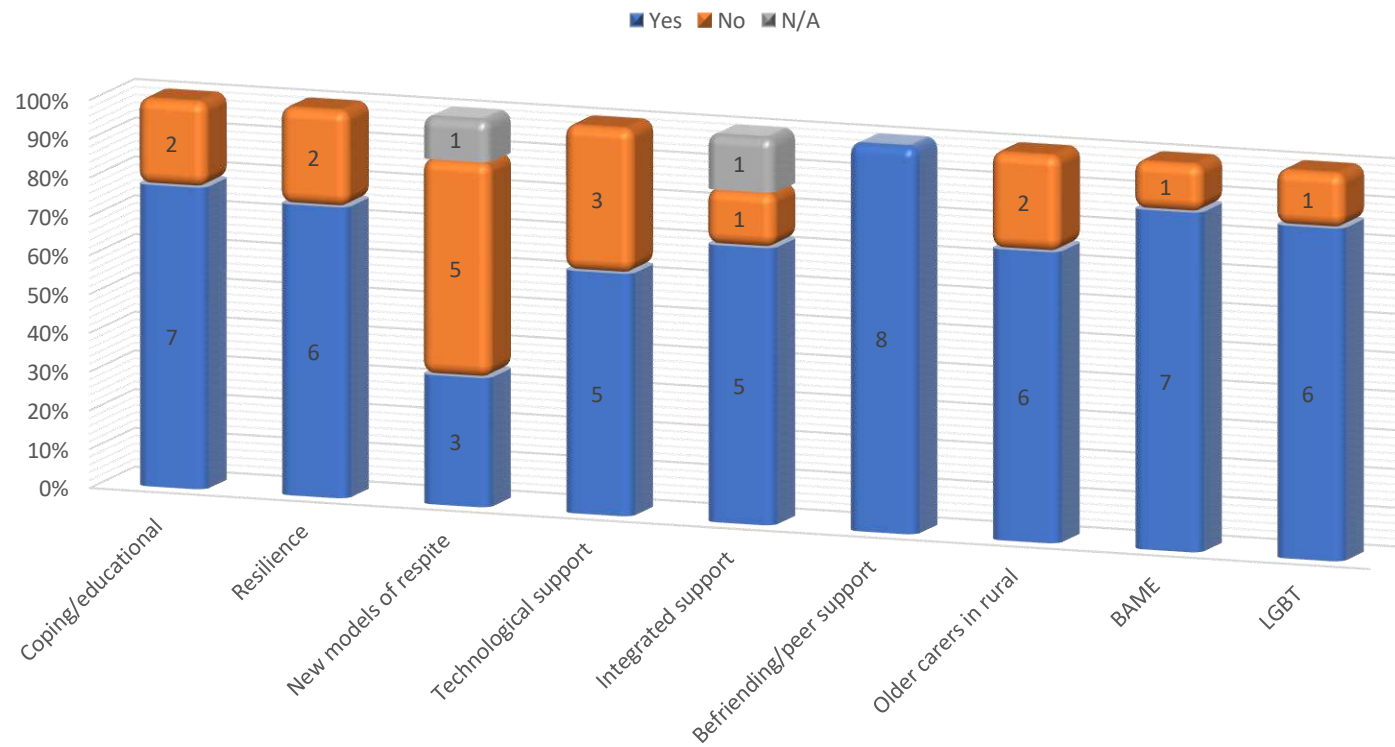
*“no specific activity currently, but all support open to all.”*

*“We do not offer specific support to this group of carers but all of our services and support are open to everyone (...) including carers of people with dementia.”*

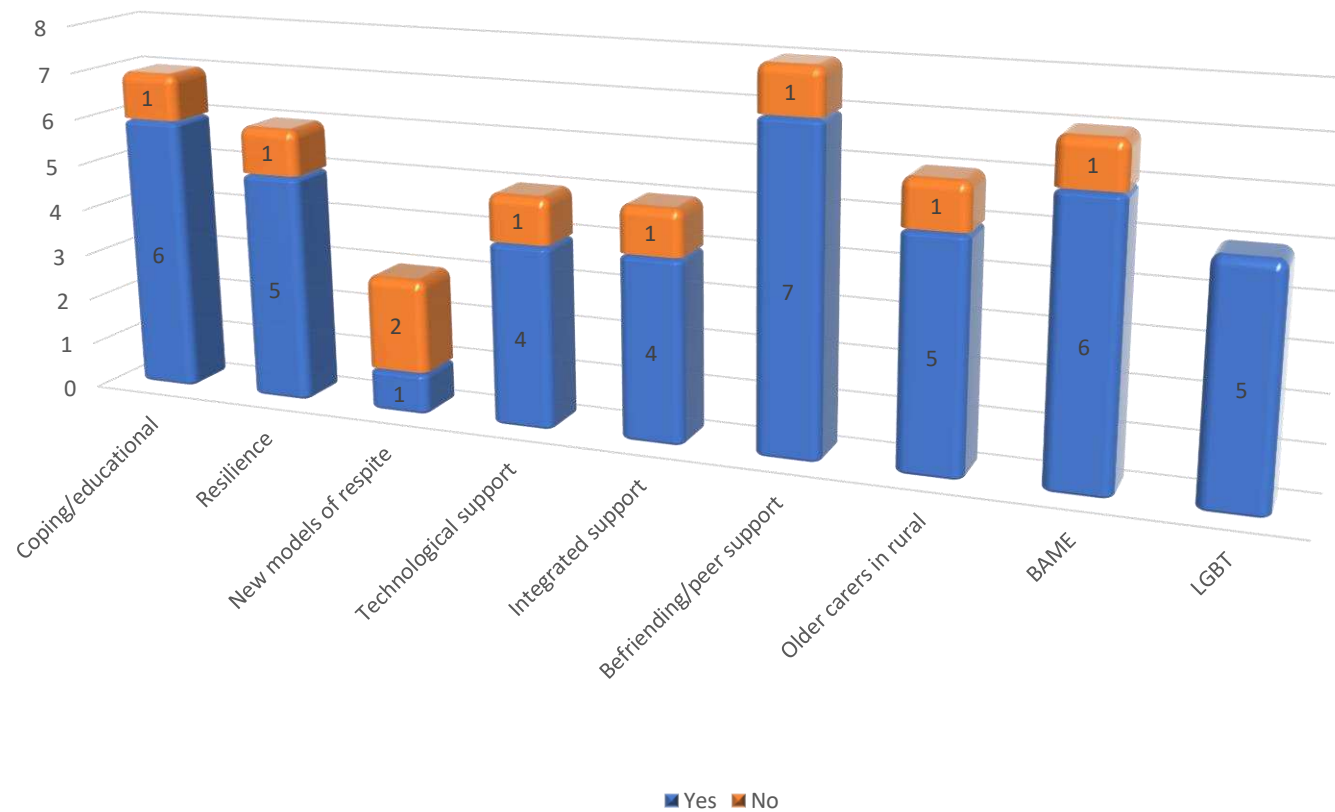
*“We are developing a leaflet for all LGBT carers, which incorporates dementia.”*

3.11 The response to specific support for carers of people with dementia, who are not also older carers (figure 3.3), painted a rather different pattern; specific models of support for carers of people with younger onset dementia were relatively absent, and again most respondents emphasised an inclusive approach in their services and support.

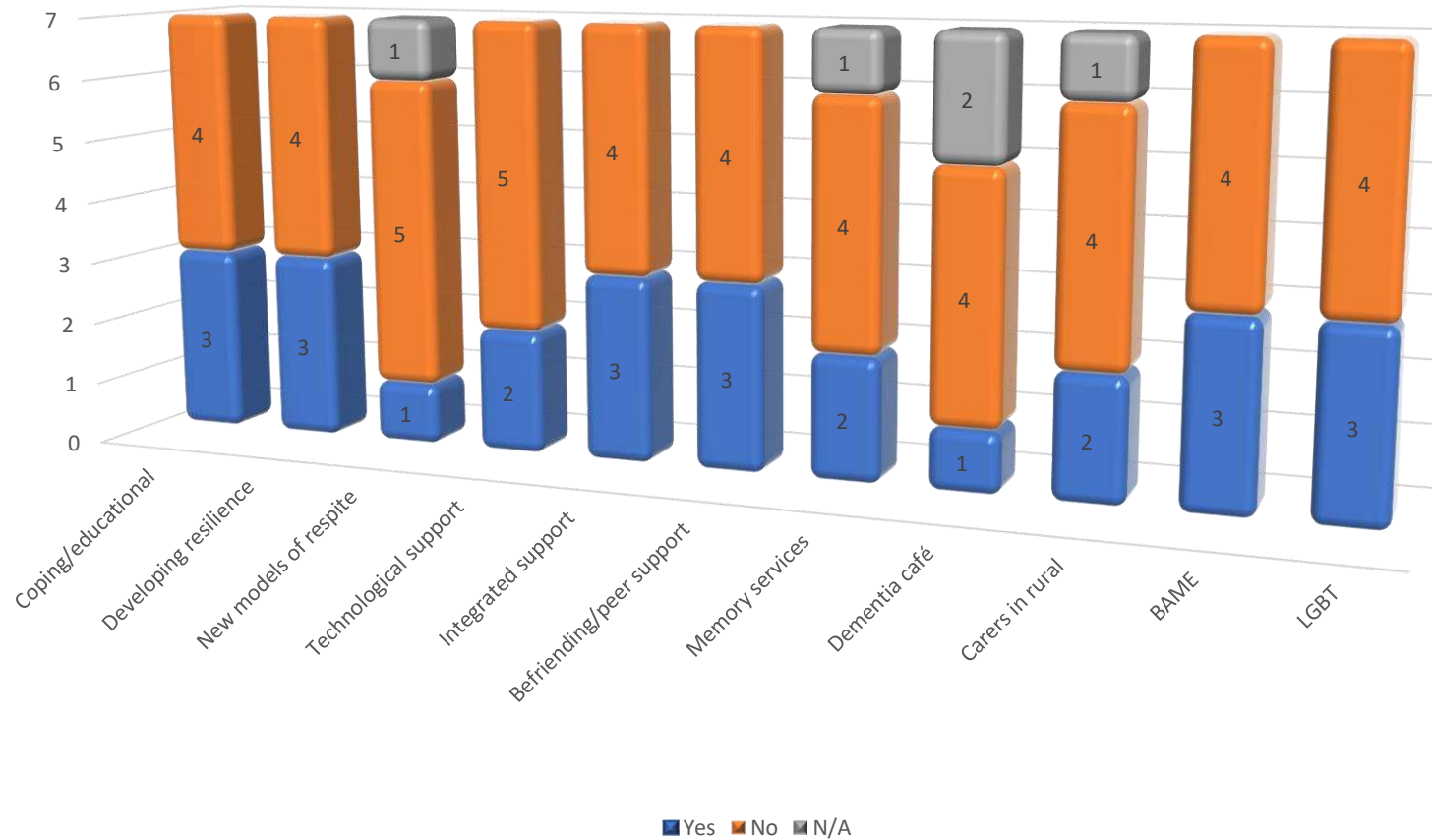
**Figure 3.1 Models of support for carers of older people (N=9)**



**Figure 3.2 Does this include carers of people with dementia? (N=8)**



**Fig 3.3: Specific support for carers of people with dementia who are not also older carers (N=7)**



- 3.12 Respondents were asked if they provided other models of support that had not been identified in the questionnaire, and a few comments were offered which underlined the fact that many local services will be developed to respond to local requirements, which may not be known in detail by national level organisations. Similarly, local activity and services are typically “reliant on the local authority or CCG funding them.” Additional comments from respondents emphasised the importance of building local community capacity and supportive communities of people with similar experiences and needs, for example:

*“We are delivering a health care navigator pilot in one area where we map and support carers and individuals to local assets to help improve their own health and wellbeing.”*

*“we capacity build local organisations to work locally with better knowledge and understanding of carers.”*

- 3.13 Some organisations that are condition-specific in their focus indicated that they are adopting a greater strategic focus on carers and including them within an approach that is directed towards ‘people affected by’ a condition. One such organisation had appointed a Strategic Carers Lead to take forward such work and ensure a focus on carers is developed and maintained as an integral part of the service offer.
- 3.14 Respondents were invited to participate in follow-up interviews to explore themes and issues in greater depth. Six of the nine respondents indicated they wished to participate, and additional contacts were identified through networks. We turn now to consider the findings from the fieldwork.

#### b) Fieldwork and Interviews

- 3.15 Fieldwork was undertaken between November 2017 and January 2018; semi-structured interviews were undertaken with 13 participants. Interviews were mainly conducted via telephone, but some were face to face; all were digitally recorded with the consent of participants, and fully transcribed. In addition to interviews, it had been planned at the outset that some visits might be undertaken to see examples of services in operation. In practice, it became apparent that often there is not a specific intervention to see, but that models of support are about a particular way of working. One visit did take place to a service developed to support people with younger onset dementia and their carers; because of the nature of this service it was possible to

observe and participate in activity without being intrusive. We will return to reflections on this initiative below.

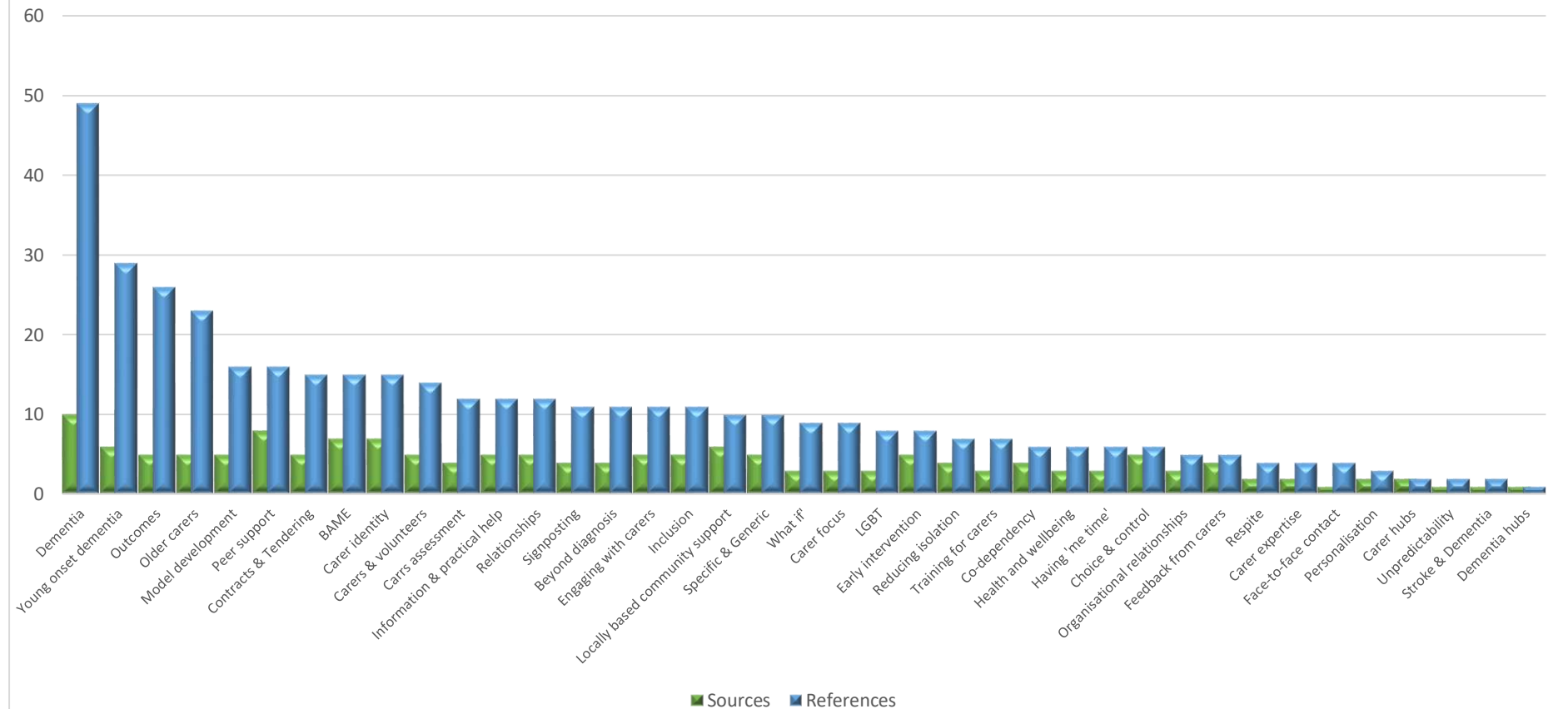
- 3.16 Fieldwork generated a rich resource of qualitative material, and analysis of interviews was undertaken using NVivo software that facilitated the identification and coding of themes and issues. Before turning to the analysis, some general reflections are worth making. It was apparent that organisations that work with carers have detailed understanding and insight from their direct knowledge of carers and their circumstances and lived experience. Many of the comments made during interviews reinforced messages and knowledge from the wider research literature. In particular, the question of carer identity is often problematic, or not recognised as such, particularly in caring between spouses or partners, where people will say ‘well, it’s what you do’, or ‘he’s my husband, of course I care’. This does, however, create challenges for identifying and supporting carers. Other findings also underlined and amplified what we know from the literature and other knowledge. This was evident both in respect of older carers and for people caring for those with younger onset dementia. In the case of the former, the interviews drew attention to the particular pressures for older carers, especially when they are coping with their own poor health and frailty. In the latter, the difficulties for people with younger onset dementia and for their families emerged as multiple and complex, not least in getting a diagnosis but also in managing the far-reaching consequences and impact.

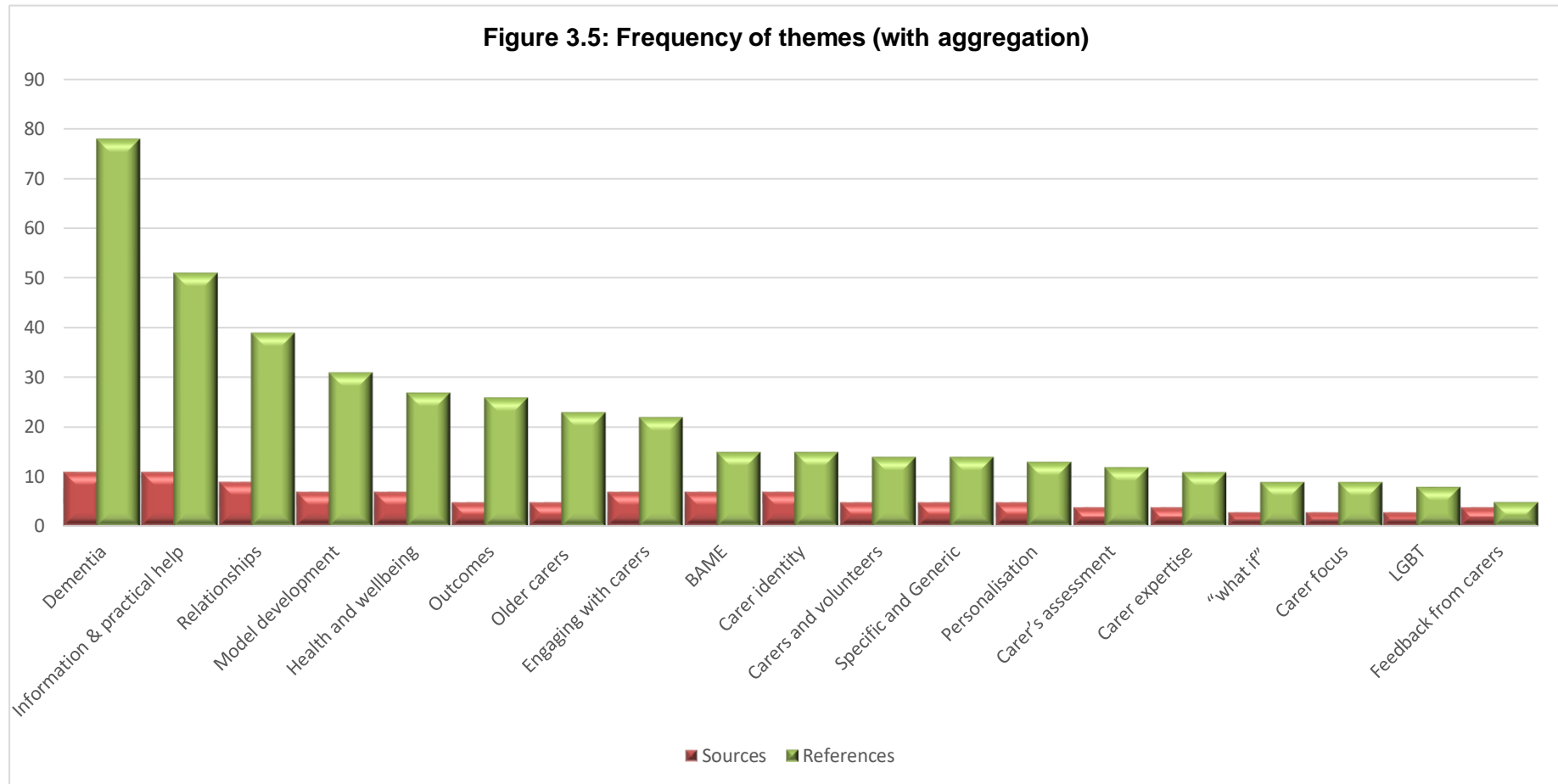
### Themes and Issues

- 3.17 Transcribed interviews were imported into NVivo and thematic analysis was undertaken. Figure 3.4 presents the key themes by frequency, while Figure 3.5 offers a thematic analysis with aggregation of themes and sub-themes. For example, the ‘parent theme’ of Information and Practical Help includes a number of sub-themes (or ‘child themes’) which are: beyond diagnosis; signposting; locally based community support; respite; carer bubs; and dementia hubs. Figures 3.4 and 3.5 therefore present the same information but in different layers of granularity. Figure 3.6 presents the same information in a slightly different visual manner by clustering sub-themes within their ‘parent’ themes. For example, the sub-themes of peer support; co-dependency; and organisational relationships, are all nested within the major theme of relationships. The relative size of the different cells reflects the hierarchy of frequency of thematic references.

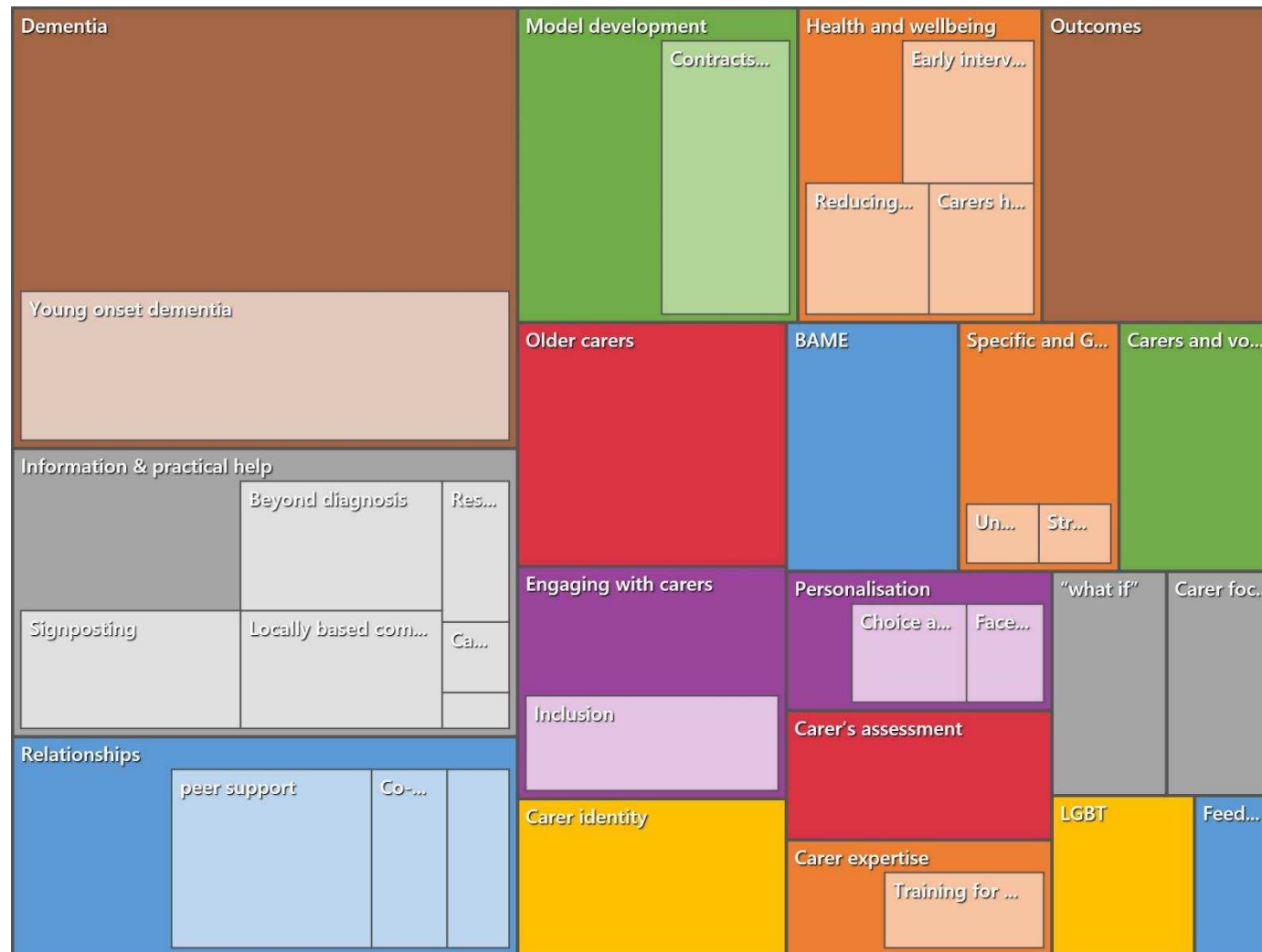


**Figure 3.4: Frequency of themes**





**Figure 3.6: Hierarchy Map of Themes and Sub-themes**



- 3.18 Some caveats need to be noted about the content of these themes – they reflect the content analysis of the interview transcripts, and do not necessarily refer to specific models of service. Figure 3.4 shows both the number of ‘sources’ (i.e. interviewees), and ‘references’ (i.e. the number of times themes were mentioned). As will become apparent in the analysis below, interviewees discussed their understanding of the situation of older carers, and carers of people with dementia, alongside describing and exploring the development of specific interventions and models of support. The pattern of themes and issues identified reflects both of these dimensions.
- 3.19 Alongside these graphic summaries of themes, we turn to consider the findings in greater detail and begin by exploring interviewees’ understanding and perspectives about older carers and carers of people with dementia. These understandings are of importance – the nature of understanding of the needs and characteristics of carers in general, and of specific groups of carers in particular, will shape and direct the development of models of care and support.

#### Older carers, and carers of people with dementia

- 3.20 The analysis in figures 3.4 – 3.6 demonstrates that dementia, younger onset dementia, and older carers were all dominant themes in the discussions with interviewees. As we have seen previously, organisations engaging with and providing support for carers typically adopt an inclusive approach towards carers of all ages, but in practice many interviewees commented on the significance of older carers. This interviewee remarked, for example:

*“The big thing, particularly with older carers, is around reducing isolation and loneliness. And so the whole sort of ethos around it is about improving both emotional and physical wellbeing for both the carers and cared-for.”*

However, very often older carers do not approach services (or are not aware of them) until a late stage in their journey:

*“(…) carers over the age of 80, you don’t come across them until they’re in an acute situation. So that’s if somebody’s been admitted to hospital or there’s been a complete breakdown of the situation and we’re not identifying people early. So, and actually people have often been co-caring for quite a long time. And so they’re very vulnerable, very isolated.”*

3.21 In addition to the isolation and hidden nature of many older carers, interviewees were also aware of the likelihood of people caring while also managing their own deteriorating health, so the impact of caring both emotionally and physically can be greater than it might be for younger carers in better health. Similarly, the co-dependency of older couples was well-recognised; as one interviewee remarked “it’s two people limping along”, and a change in health status for one or other member of the couple can suddenly change the dynamic into more active caring where it had previously been mutual support.

3.22 As the wider literature and knowledge about caring has documented, many carers do not identify themselves as such, and this is particularly likely to be the case with older carers who have been in a relationship for many years, as this comment highlights:

*“a lot of times with people ‘carer’ is a new kind of word, and if you look at it on average it takes people two years to identify as a carer. And we kind of need to change the word, a bit more about ‘do you look after somebody?’ or ‘do you help somebody?’, you know, because the word ‘carer’ – people say ‘I’m not their carer, I’m their wife!’ it’s what I do, I do it; they’re my family.”*

3.23 Older carers are also more likely to be affected by a range of other factors and effects of ageing, which can make their caring responsibilities more difficult. For example, transport can be a major consideration:

*“They’re older; they often don’t drive anymore, or the person who did drive doesn’t drive now (...) but even people that still can – there’s driving in the dark; their eyes are deteriorating, so all those frailties we all start to have as we get older prevent people from driving.”*

Some older carers are acutely aware of the implications of the loss of independence if they can no longer drive:

*“I spoke to one guy and he said, ‘you know I am still driving at 88’, he said ‘I know I need to stop any day now’, and he said ‘it will be like cutting my arm off because I’ll become so much more isolated.’ (...) ‘How am I going to get to the hospital, and how am I going to get to the doctor’s?’”*

3.24 As this carer also commented, it is not just about using a car for practical purposes such as appointments, but the ability to continue to have a life with some colour and texture:

*“At the moment I can drive my wife [down to the coast] and we can just sit and look out at the sea, and at least we feel we’re out.”*

- 3.25 For voluntary organisations providing support for carers, awareness of these wider issues – such as transport - is clearly frustrating because it is beyond their remit to be able to address these services.

- 3.26 The theme of dementia, including carers of people with dementia, was the focus of more comments and observations by interviewees than any other topic. Some of this relates to particular models of support – which we will explore later – but also to more general discourse around the topic. Although there can be considerable overlap between older carers, and carers of people with dementia, the needs of carers are both similar and distinctive. As these interviewees observed, the experience of caring can be quite different:

*“And what we did was raise the profile of the unique needs of carers and people with dementia, because it’s a very different caring experience than with, say, older people when their cognition is intact.”*

And

*“I think dementia in itself is very hard to care for. I think anything that affects somebody’s personality, their mind, is much more tricky. Because in my whole 15 years or working with carers, whether they are caring for someone with dementia or a mental health condition, or a physical condition (...) it is the mental health that they find the most difficult to manage.”*

- 3.27 As others also commented, the prospect of needs increasing over time as someone’s dementia develops can be daunting:

*“And I think when you’ve got somebody who’s caring for somebody with a degree of dementia, they also know that that level of dementia is likely to progress, and I think that is very scary.”*

- 3.28 There are also practical implications for carers, particularly for older carers who may suddenly experience role reversal for which they are ill-equipped:

*“Sometimes we find that people are looking after their spouse who’s got a dementia. You can guarantee it’s the spouse that has always done all of the paperwork – the banking, and the this, that and the other. So, you know sometimes we need to be able*

*to help people get their (...) affairs a little bit more sorted out so that that can make them a bit less anxious.”*

- 3.29 As several interviewees observed, dementia carers are not the focus of just one organisation, and many of the issues for these carers are also of a more generic nature (although some are highly specialised). There is greater awareness of dementia in general following initiatives such as [John's Campaign](#) (which champions the rights of carers to be fully involved in the care of a person with dementia, particularly when they have been admitted to hospital), and the [Prime Minister's Challenge on Dementia](#), but some interviewees questioned how much difference this really made beyond awareness-raising, for example:

*“Dementia Friends has been incredible at raising awareness. I know the question is – what happens underneath? As a campaigner, I feel that that will come, but the challenge of what to do on the back of that, so those networks locally I think are really important. They're not just located in the carers movement; they're in other places as well.”*

- 3.30 As others also remarked, a lot of the increased attention around dementia has been focused on aspects which have been relatively easy to address, as this comment highlights:

*“A lot of the support that the Government has pumped into dementia through the Prime Minister's Challenge has been focused (...) on things like the Dementia Friendly Communities, Dementia Friends and Dementia Friendly Businesses, which although it is important – is not the complex end which is both costly in resources and costly to the family to enable them to be able to cope with the changes of dementia. So again, previous little money went into post-diagnostics.”*

And

*“About 50% of the people who are living with the diagnosis are from the moderate to severe end of dementia. Everything is focused on the early bit, which is not fair – it's not fair at all. And then the money that went into research predominantly went into either cure or went into let's have a look to see if we can diagnose it earlier.”*

- 3.31 By contrast, it is argued, relatively little investment has been directed into post-diagnostic support for people and their families who are living with dementia.

- 3.32 Awareness and understanding of issues impacting on carers of people with early onset dementia revealed a different set of concerns from those affecting older carers. In particular, interviewees pointed to the substantial impact that could affect entire families because of their stage of life, and introduce extreme stress in relationships, as these comments underline:

*“They’re still in work; they’ve got a mortgage; they’ve got youngish children or children at university. They had a future ahead of them, a retirement future, that will never be realised (...) and I think that loss and that grief reaction from not only the person with dementia but their carer, can be huge.”*

And

*“The other big difference is that usually you have got people that are still of working age, or still in employment (...) The financial pressures are usually huge, and often the other partner, the non-affected partner, has got the added pressure of the financial responsibility for the family, but also in being a carer – a change of role which they wouldn’t expect at that age.”*

- 3.33 While timely diagnosis is a concern for anyone with dementia, for people with younger onset it raises a range of considerations. Diagnosis is likely to be delayed, not least because of misdiagnosis or looking for other possibilities before dementia is considered, partly because of the rarity of younger onset dementia. From the perspective of the person with dementia, they may also delay seeking diagnosis because they fear the worst or can’t believe that they could have dementia at their age, and because of the stigma which attaches to the diagnosis. These interviewees commented on the problems with diagnosing dementia in a younger person:

*“So they might be diagnosed with perhaps having a depressive illness or an anxiety state or something similar. So the medical approach is down those lines, rather than shall we look at dementia as well?”*

And

*“Very often when a person goes to the GP, or a family goes to the GP about somebody they are worried about, they will choose a different diagnosis – they will give the wrong diagnosis. They’ll say its depression, relationship problems, it’s stress at work – so they’ll give lots of other labels for what is presenting.”*



- 3.34 Some of the reasons why the condition is missed or mis-diagnosed are because it is unexpected among younger cohorts, but also because younger onset dementias typically manifest in different ways:

*“Because the majority of dementias that affect the under 65 age range are going to affect the person’s personality, their behaviour and their social functioning. Not so much the memory, although there will be some dementias that will affect the memory, but that’s usually further down the line. So all of those things are easily mistakable for another mental health issue, for stress, for work-related issues and for relationship breakdown.”*

- 3.35 Having set the scene around interviewees’ understandings and reflections on older carers and carers of people with dementia, we turn the focus to explore some of the dimensions around exemplars and models of support being developed.

### Models of Support

- 3.36 As Figures 3.4 – 3.6 describe, a wide range of activity and support for carers was identified in the course of the fieldwork. Some of this was generic – supporting carers of all types – and some was more specific, being designed for and targeted at particular groups of carers. Long term conditions – such as MS or Parkinson’s – can be unpredictable and fluctuating in their nature, which can make it particularly difficult for carers in not knowing what to expect on a day to day basis, as this comment illustrates:

*“That difficulty to plan – you can never plan anything, because they’ll plan to meet somebody or go to a support group or to do something, but that day the person (...) has a bad day, an off day, and all the plans are out the window.”*

- 3.37 There are also overlaps between different groups of carers; for example, carers of people who develop vascular dementia following a stroke are likely to have similar needs to other carers of people with dementia, and some organisations supporting either group of carers are developing joint initiatives around the interface, particularly in sharing information and signposting people where there is a crossover.
- 3.38 It would not be productive to examine in detail every item identified around models of support, and here we focus instead on the major cross-cutting, and specific, themes to emerge from the analysis, in particular:

- Information & practical help (including sub-themes of: Beyond diagnosis; signposting; locally based community support; respite; carer hubs, and dementia hubs).
- Relationships (including sub-themes of: peer support; co-dependency; and organisational relationships).
- Model development (including contracts and tendering).
- Outcomes.

Other themes will be drawn on where appropriate, and to provide additional insight.

### Information & Practical Help

- 3.39 Recognising that carers need appropriate information at the right time is a familiar refrain within carer research and knowledge, and it was frequently underlined by interviewees. For some carers there is a more direct pathway into such resources, and this is likely to be the case when there is a sudden onset of caring responsibilities, rather than a gradual accretion. In the case of stroke, for example:

*“We’re very integrated into the pathway. Healthcare staff will automatically refer people (...) where it works really well is where we’re embedded in the hospital (...) and we then meet with people and their families at those very early stages.”*

- 3.40 Getting information to people early enough, and in the right manner, was recognised nonetheless as an ongoing challenge, as this observation highlights:

*“How can we, as a voluntary organisation, ensure that our information is getting out to everybody in a village for example? (...) the over 75s and over 80s who may be hidden carers (...) how are we getting that information to them early? So I think that’s a really big issue.”*

- 3.41 Information provision and advice giving is a key aspect of support for services that have a Helpline or Advice function, and it is clear that the value of such a service can be wider than just the level of the individual ad can feed back into the organisation, for example:

*“It’s very helpful to be reminded of what people know and don’t know and the value of good expert information (...) We use people’s evidence and responses – anonymously*

of course – *in informing our policy work and submissions (...) the essence of what people are saying is very important.*”

- 3.42 People who approach organisations for advice may be ‘information seekers’ rather than actual carers – such as the adult children of elderly parents who are trying to find out how best to support an older carer, or middle-aged people who have suddenly needed to take on a greater direct caring role because of a crisis in the health of a main carer. Such people may not identify themselves as carers and may be less likely to attend a carers group, particularly if these take place during the day and they are in employment. National level carer organisations in particular are likely to make available a wide range of advice and information on-line for people to access for themselves, and the self-assessment algorithms developed in setting up such resources are designed to lead people through:

*“to help them find the right information, to help them know what they don’t know, and the questions that they didn’t know to ask, to ask them.”*

And, as an interviewee remarked:

*“You don’t know what you don’t know, until you find you don’t know it!”*

- 3.43 Information through Helplines was described by one interviewee as ‘advanced signposting’ – offering a combination of counselling, advice and signposting to other resources, because people will be contacting them for a variety of reasons:

*“Some people that phone for instance will be phoning because they can’t get a diagnosis, or they can’t get people to listen to them to get the diagnosis or referral for assessment. Some people will be phoning because they are in the earlier stages of the condition, and the family are having difficulty adapting to that.”*

- 3.44 People’s needs for information and advice will also change over time, and for carers of people with dementia, as the condition progresses needs can become more complex and demanding. The expansion of the [Admiral Nursing](#) service, for example, has developed to meet the more complex end of dementia care needs. Organisations recognise that they cannot necessarily meet all the requests that come their way, or that they are not the best people to provide a particular service, but that a key dimension of developing their ‘carer offer’ is to ensure people are aware of what is available and to direct them to it as necessary. As this interviewee described, for example:

*“Sometimes what we can do is tap people into other things; that we can act as a sort of conduit. ‘Would you like me to be able to make contact with so and so, or this particular service, ask them to come and see you?’ Because we know about them and it might be that it’s helpful – so practical stuff.”*

- 3.45 Working in this way also requires organisations to develop good working relations with other agencies:

*“Understanding and developing our knowledge of what other organisations do, especially for the carers, and where we can make use of their resources and signpost people to them, rather than trying to recreate everything.”*

- 3.46 Having a ‘life beyond diagnosis’ for people with dementia, and their carers, was referenced by several interviewees. For people with younger onset dementia this can be especially important as their life expectancy can be over an extended period and having a positive approach to quality of life is of increased importance. Access to appropriate support is critical, but some interviewees described situations in which following diagnosis of dementia, people were largely left to cope – reflecting assumptions that nothing could be done. As these comments describe:

*“It’s almost like, you get the diagnosis and that’s the end.”*

*“You know lots of GPs say ‘well we only refer if we think there’s going to be a point to referring’.”*

And

*“[people] tended to get the diagnosis, and then tended to be released back to the GP, which is fine, but the GPs generally don’t have the time or the expertise to work with people living with dementia.”*

- 3.47 Getting information and support to people can be challenging, particularly for organisations that are reliant on referrals to commissioned services. Such referrals, in turn may be conditional on diagnosis which means that GPs need to be alert to dementia, but if people and their carers are reluctant to seek diagnosis, they are unable to get support they may need. As this interviewee described:

*“People need to have a diagnosis before we can accept the referral. For those people who haven’t had that diagnosis it’s very difficult because they can’t get support through us and obviously through things like their Memory Clinic and their Community*

*Psychiatric Nurse or mental health practitioner, it's very difficult. Because there is all that support out there, but if people aren't diagnosed it's very tricky."*

- 3.48 Access to medication is also reliant on getting the right diagnosis, and while not offering a cure for dementia, some medication may be helpful in reducing symptoms or slowing progression.

- 3.49 Interviewees identified a range of locally-based community support services developed to meet the needs of carers (and the people they support). Some were particularly focused on early intervention and prevention, and in response to asking carers what would be most helpful to them, for example:

*"Support that enables them to go along with the person they care for, because quite often in the past there have been separate carers groups, which actually creates a barrier in terms of accessing support because there might be issues around the cost of care, around transport, so we look at all of that."*

- 3.50 This organisation had developed a 'family carer dementia hub' which both people with dementia and their carers could attend together, *"and it's about peer support, and any kind of information and advice they might want to have."* Although attending the group together, there were also opportunities for the group to split and do different things, with support provided by care workers for the person with dementia. Other interviewees similarly described 'carer hubs' as a place where carers could go and

*"things are really about family carers having 'me time'. So some of it might be training, and some of it might just be social contact."*

- 3.51 The benefits of joint activities involving both carers and those they care for were seen by some as supporting the caring relationship:

*"So, we've found that when people, when the carer and cared for come together, their relationship kind of rekindles or improves (...) but also the other thing we've found which is really interesting is that friendships form not just between the carers, but between people with dementia and other carers, or with people with dementia."*

- 3.52 Some services were adopting a Cognitive Stimulation Therapy model and providing structured opportunities for people to engage in discussions and express their views. Memory and reminiscence opportunities were also identified as valuable, and as this interviewee described, carers are able to relax and participate:

*“For the carers, one of the things that is very noticeable is sometimes when they first arrive at the group, they feel like they’ve got to protect [the person with dementia]. Because they’re used to being out and about where they may be, and they may feel a stigma, may be embarrassed, they may feel all sorts of things around being with the person they care for and their behaviour might be odd or whatever. When they’re in the group, you can see some of that at the beginning and then they kind of relax because they know that there is no judgement. In fact in (...) the memory project we don’t distinguish at all between who’s who. Everybody does the same thing. So everybody does all the memory stuff together, all the volunteers, staff, carers, people with dementia – we all do everything together.”*

- 3.53 The ability of services such as these to offer some respite both for carers and for those they care for was emphasised by interviewees, and other examples of innovative respite developments were also identified. One such model in development was exploring recruiting volunteers to open their own homes to three or four people with dementia, supported by a care worker:

*“So, twice a month for three hours and they would put on an activity. It’s about peer support. We’d be looking at trying to match people up in terms of interests, and then those activities and lunch. So it is again another opportunity to have a break, but also about improving health and wellbeing around people with dementia, so a range of activities and that whole sort of mixing with other people and making new friends and connections within the community.”*

- 3.54 Some of the most innovative approaches to respite were identified in respect of services to support younger people with dementia, where the emphasis was on offering age appropriate, meaningful occupation for people aged under 65 with a dementia diagnosis, while simultaneously providing structured respite support to the carers of those people through a workshop ([www.ypwd.info](http://www.ypwd.info)). Both separate and shared activities for carers and people with dementia featured within this approach. The range of activities developed was led by people indicating what they would like to try; some activities (such as a choir, an art group and a walking group) were fixed as regular workshops, but beyond that the programme of activities changed every six weeks.
- 3.55 Younger people with dementia engaged in this service were generally in their late 50s to early 60s, and following their diagnosis, *“they’re feeling very lost, and everything that they knew has stopped.”*

*“And I think we can play a small part in helping people to feel there is a life to be lived beyond the diagnosis. You know, that there are positive outcomes that people can still have, learning new skills, or doing things they’ve never tried before, just being with other people who are going through the same thing. And I think for carers that’s a huge thing as well.”*

- 3.56 In addition to the impact which a diagnosis of early onset dementia can have on a person and their family because of the consequences on their employment and income, younger onset dementia can also be harder to cope with in terms of the greater strength and fitness of the person with a diagnosis compared to someone in their 80s. If these people then develop behavioural or psychological symptoms, the situation can become difficult:

*“They need to walk; they can feel quite cooped up; things can get pretty challenging (...) their ability to run, become potentially quite aggressive – there needs to be things that will help them sleep, that will give carers more space, more of an outlet, more expression of those emotions for the person with dementia.”*

- 3.57 This service had adopted a very broad approach in its definition of respite, and one which required a flexible approach to risk assessment because of the nature of activities (including, for example, running, cycling, rock climbing and canoeing). Not being risk averse was seen as an important principle, and enabling people to try new things with appropriate support was central to this.

- 3.58 The impetus for developing the alternative, flexible model of day respite came from a health care professional who felt increasingly dissatisfied with the psychosocial support available for people with a younger onset diagnosis. The offer of day care to provide respite for carers and somewhere for the person with dementia to go was largely unacceptable to people:

*“Most 50 year olds really would not access day care where the average age of people was over 80. Nor would their carers – their spouses, partners, would say well no, that’s not appropriate!”*

- 3.59 In consulting with carers about what they wanted, it was clear that

*“what people say is that they stopped going out (...) because going out becomes a very unpredictable and unsafe thing to do really.”*

3.60 Developing an alternative model of meaningful activities as day respite was premised on the understanding that the two main predictors of someone with dementia entering permanent residential care are high carer stress, and high behavioural psychological symptoms of dementia. An approach that focused on keeping people engaged and active assumed that they would not become so anxious and agitated. We will return to the achievements of this service when we consider outcomes below.

3.61 Other interviewees were also frustrated by lack of appropriate services for people with younger onset dementia, and emphasised the value of models that are built around peer support and social opportunities, for example:

*“What I would say also works effectively are your social situations – like not calling something a ‘dementia group’ or whatever; that’s unfortunately what tends to happen, or ‘dementia café’. People don’t want to live by labels; I wouldn’t want to live by a label. So, for instance we have a group where it’s people that are living with young onset dementia, but their families as well – usually a spouse or partner – will come along and once a month we’ll go out for a meal (...) go to different venues; we have a meal, we have a chat and we have a laugh. That works effectively.”*

3.62 Similarly, focusing on what people can do, rather than what they *can’t* do can produce a more dynamic model of support than conventional day services that some interviewees described as little more than a ‘holding centre’. By contrast:

*“That’s quite useful for the families because it’s somewhere that’s safe and they can go out and do what they need to do (...) But for the people that are living with the diagnosis – unless they are doing something that they are interested in, they are not a lot of use.”*

### Relationships

3.63 Various aspects of relationships have been discussed previously in understanding older carers and carers of people with dementia, and we have focused particularly on the relationship between carers and those they care for, and the factors that can affect the quality of that relationship. Here we explore some of these issues further, drawing on the insights from the interviewees.

3.64 As we have seen, while sometimes carers will want to access services for themselves, in other circumstances they may prefer to do something alongside the person they



care for, with the opportunity to meet other carers and benefit from company and peer support. Some models of support can lead to carers establishing their own wider networks, such as this choir which provided a foundation for other activity:

*“One thing we’ve really found with the choir is that a carers network that has arisen from the choir has been amazing. I mean, they go out together, have meals together – it just kind of really started as a real seed at that choir and it’s blossomed from there really.”*

- 3.65 While some peer support is informal and spontaneous, other aspects are deliberately built into services – such as telephone befriending that offers regular contact with a volunteer with similar lived experience of caring. Other models of support also emphasised that strengths-based approaches are not necessarily about services per se and focus more on supporting people to maintain their interests than treating them as passive recipients, for example:

*“We help people who are housebound and can’t get out and really become lonely, but what I’ll often say to people is that if Fred has always enjoyed going fishing and that’s his lifelong passion, or maybe Sally was a bell ringer, it’s likely that when they are 80 they will still want to do those! They’re not going to want to have their horizons confined to day centres, this kind of club or that kind of club; what they need is something that makes these other things that have always been their lifelong passions possible.”*

- 3.66 Older carers especially may find it difficult to leave the person they support even for a short time because of the nature and co-dependency of their relationship, as this interviewee described:

*“That might be slightly different for younger carers, but with older carers you know because they might have been together for 50 years or whatever, it’s very much about co-caring. It’s how you still enable people to get that break but still feel that that’s OK – I can still see the person.”*

- 3.67 For others, there may be less closeness, and indeed tensions within the relationship, which will bring other difficulties alongside caring:

*“Everybody’s caring situation is different; every family is different. Some people may be in a very difficult situation where they might not have had a positive relationship, then they find themselves caring (...) 24 hours a day, seven days a week.”*

- 3.68 Family dynamics are also changed by caring, and these can be further complicated by feelings of guilt and responsibility when there is a genetic component – such as with some early onset dementias, as this interviewee described:

*“There’s a big degree of guilt with families that I work with because they feel they shouldn’t have had children. Also the parents of the person that’s now diagnosed can feel guilt, because they’ve inflicted that on their children.”*

- 3.69 Carers and wider family members may all have different views about the right sort of care and support, and these may differ from those of the cared for person, particularly if they have insufficient understanding of what is happening to them and the nature of their condition:

*“And then you’ve also got the difficulties of them accepting care and support from somebody that was their partner, who was probably the non-dominant partner, and from their children. Their children then become carers, which again is a massive amount of stress within that family unit and the relationships.”*

- 3.70 Not all caring relationships are entered into willingly, but also from a sense of obligation and lack of choice. The additional strains of this both on the carer and on the person they care for who may realise the person doesn’t really want to be a carer, are apparent. Support for carers in such circumstances may need to include counselling, problem solving skills and enabling carers to develop their own coping mechanisms and resilience. Understanding the nature of dementia and training carers in the implications of the condition can be a critical part of supporting them to cope, particularly in understanding the behavioural and psychological changes in a person. As this interviewee described, carers are often better able to cope with physical demands than with personality changes:

*“They say ‘I know what to do when I have to give them their dinner, or put a bandage on, or take them to the toilet. That’s practical – it’s hard and it’s tiring but you can just get on with it. But I don’t know how to manage the personality, the changing behaviours, the repeated information, the repetitive questions.”*

- 3.71 Some carers will decide eventually to walk away if they can no longer cope, while others will carry on even if they don’t like the person they are caring for. Support and advice for carers that reassures them the feelings they experience are shared by others and that there are techniques they can employ to cope more successfully can be invaluable.

*“but it’s also about sometimes giving people the permissions – if you want to call it that – to say ‘you know what, I can’t do this anymore.’ (...) so you’ve obviously got to look at the safety aspects of that; you’ve got to think well this is the end of the line. Any amount of care package is not going to achieve that; it’s gone beyond that.”*

Earlier intervention and support at the right time for people however might have made the difference:

*“If you had put some services in right at the beginning, and there was some post-diagnostic, proper post-diagnostic support...”*

- 3.72 With developments in IT and more people having access to the internet, support for carers may take different forms. The benefits of support that is virtual, or of an online forum for example, may be especially important for carers whose time is highly pressured:

*“What’s important is that it is 24 hours a day and you can connect with other people. You don’t necessarily have to travel, or get respite, or carve out that time in your busy day. You can go in at a time that suits you, so it’s really, really flexible. It doesn’t replace face to face – it’s different.”*

And

*“The other important thing is that you can be anonymous. So, in a local area you’re not anonymous and I’ve found this with research work in rural areas in particular – the challenges of anonymity, when you’re trying to keep a sense of dignity – that’s very hard.”*

### Health and Wellbeing

- 3.73 Aspects of health and wellbeing have featured in some of the previous analysis – particularly in terms of early intervention and respite, and we don’t repeat this here. However, some more general observations about the importance of health and wellbeing, and how interventions can support and improve this for carers, can be made.
- 3.74 Support for carers addressing health and wellbeing takes two main forms; on the one hand are educational and training approaches which are focused on enhancing their

knowledge and skills as carers (medication management, sores prevention, managing incontinence etc), while other interventions are concerned more directly with enhancing the health and wellbeing both of carers and those they support (through activities such as relaxation and singing). The following comments were typical of many made by interviewees:

*“Quite often in the caring role, as I’m sure you know, it’s quite stressful, and sometimes people come in and things might have been quite difficult, but they’re engaged in a very positive way.”*

*“One of the key things in the feedback from carers is about isolation and improved mental wellbeing from just having contact with other carers.”*

- 3.75 Participation in support activities can build carers’ confidence to engage more with other people and overcome isolation, for example:

*“What we find is that by offering carers activities, training, outings etc.(...) it kind of breaks down the barriers for them going and doing other things.”*

*“Carers become isolated, and then through coming to a training session or group, or activity or something, they start to maybe feel confident enough to go and access things outside again.”*

- 3.76 For some carers, engaging with others brings realisation that ‘they can still have a life’:

*“Sometimes it feels like they’ve given it all up to be a carer, but actually no – you can continue to get and have a life (...) it’s getting that balance really, and saying actually, you know, from a health point of view – especially mental health and in other ways as well – it’s really important for people to get that balance in their lives.”*

- 3.77 Getting the right balance is also about helping carers to access support at the right time, and hopefully in a way that avoids a crisis:

*“Helping people to start thinking about where they could benefit from a little bit of help before it hits the point where either the carer is no longer able to cope, or something happens with the person [they care for].”*

*“So really trying to find ways that we can avoid the crisis really and make it a more planned approach that people feel more in control of most importantly, and more informed about the decisions and choices.”*

- 3.78 Forward planning and looking ahead were seen as an important dimension of prevention and wellbeing, not least in enabling people to take some control in their situation. But these are difficult conversations and issues for carers to contemplate. Indeed, for many carers ‘the future’ includes considering the possibility of permanent residential care for the person they support, and they may not be ready to explore the implications of this. As this interviewee observed:

*“There’s a huge fear, particularly for health professionals, to bring that stuff up – that’s a tough conversation. You don’t know if the person you are talking to is ready to be thinking about it yet; you don’t want to scare them.”*

But not having the conversations risks people going into a care home in an emergency situation:

*“Something very suddenly happening, and it being incredibly traumatic and stressful for everyone involved. Whereas actually if we can find ways to be enabling people to start thinking about that, and looking into things long before that, then hopefully we can lessen the impact when that time comes.”*

- 3.79 Sometimes these conversations about contingency arrangements and the future were described in a ‘what if’ approach, covering – for example – what might need to happen if the carer was temporarily incapacitated due to illness or an accident, as this interviewee described:

*“So people are able to make an emergency plan ‘in case of’. That gets registered with the County Council (...) and then if something untoward like that happens, there’s a plan.”*

*“That helps a carer have a small sense of security that should something happen, this would be my ask.”*

- 3.80 Some carers will be reassured to have arrangements in place in the event of a crisis, while others may still find the idea of thinking the unthinkable about the future just increases their anxiety. As the interviewee acknowledged, it depends on where people are in their caring journey.”

### Model Development and Outcomes

- 3.81 The development of models of support, monitoring of their outcomes, and seeking contracts for commissioned work, were recurrent issues explored with interviewees. Securing funding for ongoing work was a concern for many, for example:

*“Fund raising is one of the biggest impediments, being able to maintain and to increase our commissioned services, and of course in an atmosphere where health and social services have been in turmoil (...) there are all sorts of implications.”*

- 3.82 Indeed, the impact of austerity on public services, and on the availability of support for third sector initiatives was widely cited, and some of the interviewees either did not know if they would have a job in the next financial year, or had already been told that their contract was finishing because of lack of funding. People described a sense of operating ‘hand to mouth’, and the problems of uncertainty in the absence of robust and reliable funding streams. The increase which some organisations had experienced in the length of tenders offered by commissioners was seen as particularly beneficial, as working on short term, one or two-year contracts, created significant difficulties for organisations:

*“There’s a lot of uncertainty – we train and we develop staff, and we have such brilliant passionate staff and then they have to move on because we don’t know from one year to the next what’s happening.”*

And

*“This is a problem for lots of organisations – the NHS commissions on a yearly basis. So, it is very hard if you’re a small organisation. You want staff to be on permanent contracts, but it isn’t safe that you’ll get the funding next year. So we had a few years of that. And then when the Better Care Fund came out we took our data to the Clinical Commissioning Group and now we get some of our funding from them.”*

- 3.83 Getting commissioners to see the value of what organisations were providing was seen as an ongoing challenge, for example:

*“I think [the challenge] for the organisation is obviously keeping up funding streams, getting people to continue to recognise that we have a valuable role in supporting this group of people.”*

3.84 Organisations that believe they have developed a successful model of support that is worth sharing and growing are keen to ‘spread the word’, but the process for doing so is neither straightforward nor without cost, and people *“don’t necessarily know which doors to knock on to make that happen.”*

3.85 Organisations that have been commissioned to provide and develop particular types of service need to report on their activity, but the nature of this reporting and the outcomes that are requested were not always seen as the most helpful or relevant. Often monitoring is little more than activity counting – the numbers of people using the service etc. Sometimes this is indicative of the way that relationships have been established with commissioners, as this comment highlights:

*“Mainly numbers, but we’re very fortunate because we have a very good relationship with the commissioner (...) he’s one of our biggest advocates because he’s seen for himself how we do things and the benefits. But again, if it was someone else coming in, we would have to look at how we evidence it.”*

3.86 Some interviewees referred to ‘anecdotal evidence’, and clearly qualitative indicators of people’s experiences of using support will be of importance. However, others acknowledged that their activity was – or had been – undertaken in ‘an evidence free zone’, and recognised that this needed to change:

*“We didn’t have the evidence of why it was effective. We knew it was effective, but we didn’t have the concrete evidence. Most people want quantitative as well as qualitative research, so what we did is we had a look at – usually people want to measure how many people we’ve seen, how much does this cost, and then did this delay an admission to a care home, did it delay admission to hospital, or did it prevent either of those things? And then you can put a cost figure to it; and that’s what we did – it’s as basic as that, and this has actually proved the saving.”*

3.87 Complications can arise when services are commissioned through the NHS but it appears that the benefits accrue more to local authority social services.

3.88 Focusing on quantitative outcomes and key performance indicators may not tell the whole story, for example in relation to quality and people’s experience of using the service, as this interviewee described:

*“Actually, you know what – we also want to measure quality. So we will work with the families, we’ll get feedback from the families (...) so the majority of commissioners will*

*ask precisely how much does it cost, how much does it save? And they'll only ask about the qualitative once you push them to."*

- 3.89 Knowing what to measure – and how to do it – is important both for the providers of services, and for those who commission them. As this interviewee remarked,

*"I think we can demonstrate better outcomes (...) than with the stick of 'you need to produce this outcome, that outcome', some of which is quite meaningless. So we're kind of measuring the wrong things a lot of the time!"*

- 3.90 The outcomes which do matter are those that make a difference to the health and wellbeing of people in need of care and support, and of their carers. As this interviewee described in relation to an innovative model of support for people with young onset dementia:

*"Whenever the CCGs say 'how many admissions do you think you've avoided?' it's very difficult, because one year you'll get a cluster. So I always say, you know, what we're going to measure is behavioural and psychological symptoms and carer stress because we know those are the, the research shows those are the predictors (...) there is no doubt that because of the levels of engagement and meaningful activities, the model I would say is delaying people going into 24 hour care."*

- 3.91 Measurement in the clinic of the behavioural and psychological symptoms of people with young onset dementia who were engaged with the project over two years has indicated scores halving and staying consistently low, and low levels also of anti-psychotic prescribing which would usually be high for a younger group of patients with dementia. Moreover,

*"What we've found (...) when people accessed the charity, the number of mental health worker contacts and doctor contacts basically reduced again by about half."*

- 3.92 Unusually, the contact information for people using the service was directly linked to their clinical notes and made it possible to see the relationship between attending sessions run by the charity, and reduced NHS contacts. As a psychiatrist linked to the service observed, this seamless information was a huge contrast with usual practice:

*"If my older patients are going through a day centre, I don't know anything about what goes on at the day centre, because there is no way of connecting that information back."*



- 3.93 The importance of collecting and evaluating appropriate outcome information, and being able to link data to an intervention, is an issue we will return to in Section 4.

#### BAME & LGBT Carers

- 3.94 As we discussed earlier in this section, responses to the on-line questionnaire on models of support for BAME and LGBT carers were less than illuminating and generally indicated that these needs were addressed within an inclusive approach. We sought to explore this more fully in the course of interviews and fieldwork, and interviewees demonstrated a greater awareness of the need for a more nuanced approach. People were sensitive, for example, to the importance of raising awareness of conditions such as stroke and dementia within different minority ethnic communities, and of understanding the implications for carers, without making assumptions or generalisations.

*“We have lots of projects going on where we’re actively going into different environments so that we can engage directly with BAME communities. So that’s something, and we need to do an awful lot more of that.”*

- 3.95 Clearly, as some interviewees pointed out, it makes no sense to talk about ‘BAME groups’ as if they are a single community, for example:

*“Because of the length of time that different populations and individuals have been here, second and third generations are very different.”*

- 3.96 Some interviewees described having “done a lot of work” with different communities, with the result that services were reasonably diverse, but recognising that “there are some groups that are not represented.” Services that are based in areas with large minority ethnic communities reported having developed approaches around specific services and support for different communities:

*“They have positively recruited from those communities in order to be able to support carers, for the carers to understand that they are there for them. So they’ve recruited from the Afro-Caribbean community, and from the South Asian community, and they have people who speak the language, and they run groups that are really well attended.”*

- 3.97 Trying to ensure that services are appropriate and responsive to needs raises questions about the development of separate or inclusive models, and both are likely to be required. Some services that wish to be inclusive nonetheless have a ‘trickle’ of referrals or approaches from non-white carers, and recognise that while this might reflect the local demography in some localities, it is also about ensuring that information reaches communities appropriately:

*“We’re trying to be proactive; we’re explaining a bit more about early onset.”*

And

*“I’ve looked at our memory clinic statistics and our referral for the memory clinics for BAME, and it’s the same percentage as the population. So, we’re seeing who we should be seeing – even though it’s small numbers.”*

- 3.98 Services that are not receiving many (or any) referrals for people from minority ethnic groups described the challenge of being accessible while not developing specialist services to meet unknown demands:

*“It’s like a kind of Catch 22 – until we get the referrals it’s very hard to then know how to help that group, that person and how to meet their needs (...) we have to be reactive once we’ve received the referral (...) then, right how do we make sure we are as inclusive as we can be for this person?”*

- 3.99 Response to LGBT issues within carer support was less developed; and some interviewees acknowledged this was something that “should be on our horizon”. As this interviewee commented,

*“The interesting thing is that the needs are exactly the same; where the challenges come out is in attitudes and approaches.”*

- 3.100 It was also remarked that in many ways this is a generational issue, and campaigning groups (such as Stonewall) have focused on establishing equality for people’s basic rights. But as the population ages, people who have grown up with those rights will speak more openly about wider issues including caring:

*“So, I think that will come out more to the fore. There are all sorts of issues: finding appropriate care; being treated appropriately, having to discuss your relationship and be very open about it.”*

- 3.101 One interviewee referenced a memory café that has been established as a pilot specifically for the older LGBT community living with dementia in London, but this was a rare example of a service responding to this community and validating the need for a separate and safe place.

### Summary

- 3.102 In this section we have presented the key findings and analysis of exemplar models of support for older carers, and carers of people with dementia, identified through research with a sample of third sector organisations. We have drawn together the findings and insights generated both from an on-line survey, and from further in-depth work based mainly on semi-structured interviews.
- 3.103 We have identified a number of key themes which also reinforce the messages identified from other research and knowledge about supporting carers. Befriending and peer support, and educational/coping support to develop carer resilience, emerged as key emphases from the survey, and were reinforced in interviews. Multiple additional themes were also identified, and our analysis has focused on highlighting the findings from the themes and sub-themes which together attracted the most attention. In particular, this included information and practical help; relationships; model development, and outcomes. We have demonstrated that it is not always a specific intervention alone that makes a difference to carers, but it is the style of the service, and a combination of elements that provide valued support for carers and contribute to their resilience and capacity to sustain their identity. In particular, it is not simply the 'what' of a service, but also the 'how'; or what is distinctive about the approach of a service or a specific intervention that is valued by those who use it.
- 3.104 As we have summarised, interviewees described some general styles of approach and generic carer support (including, for example, information and advice; carer groups and respite), and the underpinning inclusive values which informed these, alongside some more specific models and innovations for particular groups of carers. However, it was relatively rare for organisations to develop such models within a framework that articulated a theory of change. This is an important finding with implications for future initiatives, as we address in Section 4. Without clarity over the nature of a given intervention, and the intended objectives, it is not possible to draw firm conclusions about achievements or outcomes – or indeed to have clarity over the appropriate parameters of those outcomes and how to measure them. Such conclusions are

relevant - and indeed vital - both to providers seeking to develop and extend the reach of their services, and also to commissioners wanting to support such developments and needing to establish more sophisticated and accurate ways of evidencing effectiveness that progress beyond enumerating activity.

## 4. Conclusions and Recommendations

- 4.1 This project to scope exemplar models for older carers, and carers of people with dementia, through engaging with third sector organisations, has been revealing and has generated rich qualitative material shedding light on local understandings of carers' support needs and the development of appropriate services and support. In this section we reflect on some of the main conclusions and consider the implications for future commissioning.
- 4.2 This is a timely piece of work that fits well with the continued 'Commitment to Carers' initiative from NHS England (NHS England, 2014b, 2015a, 2015b), and provides opportunities to take further steps in satisfying the mandate from the Department of Health to become "dramatically better" at involving patients and their carers, and in enabling them to define 'what matters most' in their experience of services.
- 4.3 As we explored in Section 2, we have located the findings of this project within the context both of the national policy framework, and of the wider research literature and knowledge about carers and models of support. Policy objectives relating to care and support for adults and for those who care for them are set within the objectives of the 2014 Care Act (HM Government, 2014), and are concerned particularly with promoting wellbeing, and with delaying and preventing care and support needs while supporting people to live as independently as possible. Other relevant objectives include the duty to cooperate and to achieve closer integration of care and support and health services. The NHS Five Year Forward View, and the subsequent 'Next Steps' further reinforced the importance of supporting carers, focusing particularly on the most vulnerable, including older carers (NHS England, 2014a, 2017).
- 4.4 The key messages from research and knowledge about carers highlight the distinctive needs of older carers, and carers of people with dementia (including people with young onset dementia). Evidence about 'what works' is relatively thin or inconsistent, but there is emerging consensus around the effectiveness of interventions to enhance carers' skills and knowledge, and the value of interaction with people outside carers' normal networks (Henwood et al., 2017; Parker et al., 2010; Thomas et al., 2016). Other analysis has pointed to the centrality of strengthening carer resilience, as the essence of what connects disparate carer support strategies and interventions (Parkinson et al., 2016).

- 4.5 Our project findings – based on sequential stages of an on-line survey and more detailed qualitative interviews – have been reported and analysed in Section 3. We took the emerging findings and conclusions from this work to a consultation workshop with key stakeholders in February 2018, and there was widespread support and endorsement of the conclusions. Reflections and discussions at the consultation have further informed our analysis. A summary of the event is included in Appendix 1.
- 4.6 Our conclusions have echoed and reinforced many of the central messages identified in the wider research and knowledge about supporting carers. Thus, for example, we found befriending and peer support, and approaches focusing on developing carer resilience were highly valued. Furthermore, we have underlined that the style of support, and the manner in which it is provided can be crucial. Thus, support is not always about a single intervention, but about a combination of factors, reflecting both the ‘what’ and the ‘how’ of support.
- 4.7 As we discussed in Section 3, evaluating the effectiveness of interventions, and assessing the outcomes achieved, is often relatively unsophisticated and undeveloped. There is often a need for greater clarity about the purpose and objectives of interventions, and how these are to be achieved (in research terms, what is referred to as a ‘theory of change’). In turn this creates greater clarity about appropriate reporting and performance measures. This is of particular importance in respect of commissioned services, and requires CCGs and local authority partners, for example, to have a better understanding of the objectives of interventions developed by third sector bodies, and the relevance of outcome measures to assess achievement. It is important that these address both quantitative and qualitative dimensions, and moves beyond basic counting of activity, while not making unrealistic expectations about achievements (such as demonstrating reduced residential and hospital admissions) over a short time scale, and without taking account of wider variables that may impact on delivery.
- 4.8 As we have also seen, in order for third sector bodies to develop models of support, to have opportunities to examine effectiveness and to scale up successful initiatives, some level of security is required with commissioning. Short term contracts or annual tenders are not conducive to such developments, particularly for smaller organisations that do not have the capacity to invest in project development and staff employment without a reliable funding stream.

- 4.9 We have identified some innovative developments for older carers and carers of people with dementia, and also highlighted some areas where further attention is needed (such as with the particular needs of BAME and LGBT carers within these groups). There would be merit in exploring more fully some of the models and in supporting their adoption in other sites. We recommend that NHS England should give consideration to supporting such developments through further testing in pilot sites. On the basis of our analysis, Box 4.1 summarises some of the directions that would seem to offer the most promising opportunities; in all of these scenarios it will be necessary to develop appropriate and relevant monitoring and evaluation approaches which should be co-produced between commissioners and providers if they are to produce meaningful metrics and outcome evidence.

**Box 4.1: Further development of models**

- **Building carer resilience** through techniques for coping and understanding: providing the right information and training for carers in understanding the condition of the person they support, and in developing techniques to manage the demands.
- **Reducing isolation and loneliness:** this is a major factor in addressing the mental health and wellbeing for carers and in preventative intervention. Social contact and peer support are particularly valuable components.
- **Living a life beyond diagnosis:** this is especially relevant for people caring for someone diagnosed with dementia. Recognising that the condition is progressive, but taking the opportunities to enhance daily life. Crucial to this is appropriate and timely diagnosis and referral, which have major implications for GPs and other health and care staff.
- **Reimagining respite:** recognising that respite is also about breaks from the usual routine for both carer and cared for person. Some features of innovative approaches for people with younger onset dementia that emphasise meaningful activity and engagement need to be more widely adopted. What can this look like for older people and their carers?
- **Space and scope to expand:** commissioning models of support within longer timeframes that allow scope for development and achievement and do not cause additional pressures of year on year uncertainty of funding.

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## Appendix 1

### Consultation workshop on emerging findings, the Open University, Milton Keynes, 26<sup>th</sup> February 2018

A consultation workshop on the NHS England Commitment to Carers project (identifying exemplar models and support for older carers, and for carers of people with dementia) took place at the Open University on 26<sup>th</sup> February 2018. The workshop was facilitated by Mary Larkin, Alisoun Milne and Melanie Henwood. Jennifer Kenward (Head of Patient Experience and Carers Programme Lead) commissioned the project on behalf of NHS England and also participated in the workshop. In addition, graphic facilitator Pen Mendonça captured discussions through live sketchnoting and her completed graphics are reproduced in this document.

The workshop participants were the following:

Tim Anfilogoff, Herts Valley CCG  
Jeanne Carlin, Carer  
Margaret Dangoor, Former carer  
Manik Deepak-Gopinath, Open University  
Karen Harrison Denning, Dementia UK  
Jacqui Hussey, NHS, Berkshire  
Nicola Jarvis, Strategic Planning Board, Leicester  
Sarwar Khan, NHS England  
Alison Maulin, Leicestershire  
Sarah Murray, Carers Trust  
Elaine Roberts, The Stroke Association

Following a presentation by Melanie Henwood on emerging findings from the project, the workshop participants participated in small groups discussions considering the following key issues:

- Developing models of support: what are the barriers and opportunities?
- Gathering evidence: what needs to be measured or evaluated?
- Making the case to commissioners: is it sufficiently compelling?

The first graphic below summarises the main emerging themes of the project, many of which have featured in this report; the second graphic captures the main themes that were identified in the workshop group discussions. These points are also summarised in the following bullet points.

- Information and evidence needs to be made easily accessible to commissioners.
- Planning of services needs to connect to carers' views and experiences.
- Carers are all individuals and unique; focusing on processes can overlook people.
- People live in relationships; what is the benefit of support to the relationship?
- The 'inverted umbrella' metaphor – the carer is represented by the fabric of the umbrella, and the person they support is perched on top of the handle; the various interventions of care and health services are the umbrella spokes (making up a small proportion of the total support of the person), but this is a frail and unstable structure – some spokes are missing or broken.
- Services and support need to be better integrated and user-led; what is the role of public health?
- Identifying carers can be impeded by using the wrong words and terminology.
- Outcomes measures are often inappropriate, don't reflect what matters to carers, and take a short-term perspective.
- There are significant transactional costs for third sector providers in short-term commissioning.
- Outcomes-based commissioning needs to be grounded in what works for carers but not over-specify the how and what of delivery.





Identifying Exemplar Models and Support for Older Carers and All Carers of People with Dementia, Open University, February 2018, graphics by @MendoncaPen

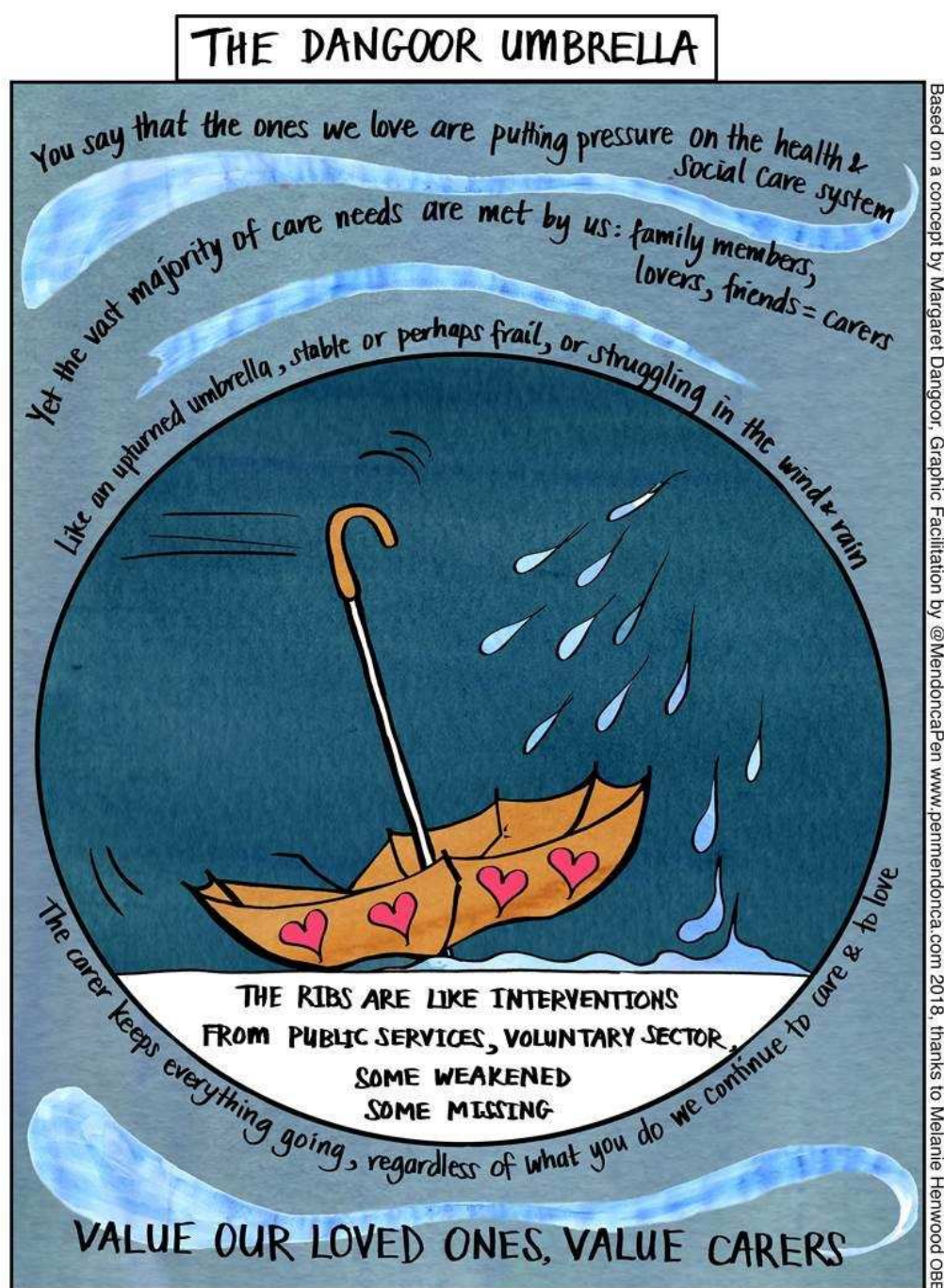




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**Footnote:** The analogy of the 'upside down umbrella' was outlined at the consultation workshop by Margaret Dangoor, a former carer. She explained that the idea of an umbrella adrift on the water represented the precariousness of many caring situations. Carers provide the fabric of the umbrella and hold everything together, while interventions from statutory and voluntary sector services are represented by the ribs, but these are often missing or broken. In liaison with Margaret Dangoor and Melanie Henwood, Pen Mendonça subsequently designed the graphic reproduced above.